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SB 832: Public Institutions of Higher Education - Students with Chronic Health Conditions - Case Manager Senate Education Health and Environmental Affairs Committee

March 2, 2022

Position: Support

The Arc Maryland is the largest statewide advocacy organization dedicated to protecting and advancing the rights and quality of life of people with intellectual and developmental disabilities and we support SB 832. Sb 832 promotes inclusion and accountability, and is a critical step to ensure equitable access to higher education for individuals with disabilities.

There are a number of resources on college campuses in Maryland that could be helpful and necessary for the success of students with chronic health conditions but often students are either unaware of the service or face disability-related barriers to accessing the service. This bill would require each institute of higher education in Maryland to provide case management services to students with chronic health conditions to support students to utilize existing resources. Case managers would help students with chronic conditions by serving as a liaison or ombudsman of sorts: coordinating services between different departments, providing information to students and help to access supports and services, collect data and information on programs, services, needs, and outcomes, and support other efforts across campus and community systems to reduce barriers that impede a student's academic success.

Students with intellectual and developmental disabilities have the lowest rates of both competitive employment and college enrollment compared to all other disability groups. Yet, students with intellectual disabilities who complete an inclusive postsecondary program achieve better employment outcomes, expand peer and social networks and increase independence.¹

The 2021 Maryland Higher Education Commission report on Students with Disabilities 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. While this is a large number, it admittedly does not capture all students who have disabilities not registered with the institution of higher learning who have not self-disclosed a disability or asked for learning accommodations.

In high school, although children with chronic illness have greater numbers of days absent from school than their healthy peers, the vast majority are able to graduate. Despite having similar high school graduation rates, research indicates that young adults with chronic illness are only half as likely to graduate from college as their healthy peers. Disruptions in peer relationships, isolation, loneliness, and loss of supports (formerly available in high school) are contributing factors.

While the Individuals with Disabilities Education Act provides for education-related services and supports for children with disabilities, ages birth to 21, it does not provide supports people with disabilities needed for academic success in college, such as education coaches, assistive technology, tutors, or other supports required to learn, socialize and engage with others, and exercise independence.



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We understand that several Maryland campuses offer some form of case-management services to students with Chronic Health Conditions, but the effort is not consistent across the state, and services vary from institution to institution.

The state invests significant primary and secondary school resources for young students with disabilities to prepare them for adult work or continuing education life. Some students with IDD are able to access Developmental Disabilities Administration services as a Transitioning Youth, but students with chronic health conditions who elect to go on to college may not qualify for DDA services and supports. These young people experience an abrupt cliff upon exit from high school. What many need, however, is continuing support through the college years so they may be successful in college, graduate, and ultimately contribute to the workforce.

Students with disabilities who attend college with the services and supports necessary not only acquire valuable knowledge and skills but learn independence. Providing case management for students with disabilities and chronic health conditions would take us another step toward increasing equitable access and opportunity to college experiences for all.

Please contact: Ande Kolp, Executive Director of The Arc Maryland akolp@thearcmd.org

 $[^]i\,https://education.umd.edu/news/12-21-20-maryland-developmental-disabilities-council-funds-terps-exceed-inclusive-postsecondary$

ii https://mhec.maryland.gov/publications/Documents/Research/AnnualReports/2021ReportonStudentswithDisabilities.pdf

iii https://www.researchgate.net/publication/265924640_College_Freshmen_with_Chronic_Illness_A_Comparison_With_Healthy_First-Year Students

https://www.researchgate.net/publication/265924640_College_Freshmen_with_Chronic_Illness_A_Comparison_With_Healthy_First-Year_Students- reference National Longitudinal Study of Adolescent Health 2014

^v https://www.researchgate.net/publication/265924640_College_Freshmen_with_Chronic_Illness_A_Comparison_With_Healthy_First-Year Students

JCR_StudentsWithChronicHealthConditions_2021_SB 83

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Report on Students with Chronic Health Conditions

November 2021

Lawrence J. Hogan, Jr. Governor

James D. Fielder, Jr., Ph.D. Secretary of Higher Education

MARYLAND HIGHER EDUCATION COMMISSION 6 North Liberty Street, Baltimore, MD 21201 www.mhec.maryland.gov Boyd K. Rutherford Lt. Governor

Dennis R. Schrader Secretary of Health

MARYLAND DEPARTMENT OF HEALTH 201 W. Preston Street, Baltimore, MD 21201 www.health.maryland.gov

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. 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.

 $^{^{7} \, \}underline{\text{https://www.acha.org/NCHA/ACHA-NCHA_Data/Publications_and_Reports/NCHA/Data/Reports_ACHA-NCHAIII.aspx}$

27822 63416 J. Ongoing or Chronic Conditions Trans/GNC n = The questions for the ongoing or chronic conditions 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. *Of those ever diagnosed, those reporting contact with healthcare or MH professional Mental Health diagnosed with the following: within last 12 months Cis Women Cis Men Cis Women Gender Non-Cis Men Total Gender Non Total conforming conforming ADD/ADHD - Attention Deficit/Hyperactivity Disorder 38.2 Alcohol or Other Drug-Related Abuse or Addiction 40.8 Anxiety (for example: Generalized Anxiety, Social Anxiety, Panic Disorder, Specific Phobia) Autism Spectrum Bipolar and Related Conditions (for example: Bipolar I, 62.0 74.4 73.0 71.6 II, Hypomanic Episode) Borderline Personality Disorder (BPD), Avoidant Personality, Dependent Personality, or another personality 55.9 64.1 64.4 63.4 Depression (for example: Major depression, persistent depressive disorder, disruptive mood disorder) 14.4 51.1 71. Eating Disorders (for example: Anorexia Nervosa, Bulimia Nervosa, Binge-Eating) 0.1 0.0 0.1 12.5 11.1 Gambling Disorder 0.4 6.4 6.0 54.4 Obsessive-Compulsive and Related Conditions (for example: OCD, Body Dysmorphia, Hoarding, Trichotillomania and other body-focused repetitive behavior disorders) 11.9 4.6 52.. 65.2 61.4 PTSD (Posttraumatic Stress Disorder), Acute Stress Disorder, Adjustment Disorder, or another trauma- or stressor- related condition 20.0 68.5 Schizophrenia and Other Psychotic Conditions (for example: Schizophrenia, Schizoaffective Disorder, Schizophreniform Disorder, Delusional Disorder) 55.1 0.3 56.0 Tourette's or other neurodevelopmental condition not already listed 21.5 50.0 39. Traumatic brain injury (TBI) 1.0 1.1 2.1 Cis Men Gender Nonconforming Students reporting none of the above 61.1 Students reporting only one of the above 14.0 Students reporting both Depression and Anxiety 10.1 21.6 44.4 19.3 Students reporting any two or more of the above (excluding the combination of Depression and Anxiety)

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)

 $[\]underline{https://mhec.maryland.gov/publications/Documents/Research/AnnualReports/2021ReportonStudents with Disabilities}.\underline{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" 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 &}lt;a href="https://www.activeminds.org/blog/new-fall-gear-from-the-active-minds-shop/?gclid=Cj0KCQjwkIGKBhCxARIsAINMioJAsLznw_flVeU47k13a0GgBqddY6n4ihXW4AXqxTfxnqSFgWR4hw8aAhP6EALwwgB">https://www.activeminds.org/blog/new-fall-gear-from-the-active-minds-shop/?gclid=Cj0KCQjwkIGKBhCxARIsAINMioJAsLznw_flVeU47k13a0GgBqddY6n4ihXW4AXqxTfxnqSFgWR4hw8aAhP6EALwwgB

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)

Workgroup Members (in alphabetical order by name of organization)

Name	Organization	Title
Marcia Wiedefeld, MA, CRC	Loyola University	Director, Disability Support Services
Tina Backe	Maryland Department of Health	Coordinator, CHW Program, Office of Population Health Improvement
Amanda Klein, MPH, CHES	Maryland Department of Health	BRFSS and Data Manager, Center for Chronic Disease Prevention and Control
Jamie Perry, MD. MPH	Maryland Department of Health	Director of School Health, Office of Population Health Improvement
Kristi Pier, MHS, MCHES	Maryland Department of Health	Director, Center for Chronic Disease Prevention and Control, Prevention and Health Promotion Administration
Emily A. A. Dow, PhD	Maryland Higher Education Commission	Assistant Secretary, Academic Affairs
Irnande Altema, Esq.	Maryland Independent College and University Association	Associate Vice President for Government and Business Affairs
Ruth N. Agwuna, MDFAAP	Morgan State University	Director, Health Center
Patience Ekeocha, DNP	Morgan State University	Associate Director, Health Center
Kate Weeks, MS	Morgan State University	Director, Student Disability Support Services
Deborah Bello	St. Mary's College of Maryland	Assistant Director, (Health) Wellness Center
Annesha Edwards-Carter	St. Mary's College of Maryland	Coordinator of Diversity and Civic Engagement
Spyridon Marinopoulos, MD, MBA	University of Maryland, College Park	University Health Center and Chief Medical Officer
Zakiya Lee, PhD	University System of Maryland	Assistant Vice Chancellor for Academic and Student Affairs

SB832_Vassar_Schinella.FAV.pdfUploaded by: Margot Schinella

Position: FAV

VASSAR COLLEGE DEPARTMENT OF HEALTH SERVICES

SB 832/HB 1098

February 26, 2022

Re: Maryland Higher Ed Legislation for Students with Chronic Health Conditions

To Whom It May Concern:

My name is Margot Schinella and I am a Family Nurse Practitioner and the Director of Health Services at Vassar College in Poughkeepsie, New York. To provide context, Vassar College is a highly selective, residential, coeducational liberal arts college with approximately 2,500 enrolled students. Our campus culture seeks to promote an environment of equality, diversity, and inclusivity.

I am reaching out today in support of legislation that would require public institutions of higher education to designate a case manager. In my experience, case managers are an extremely valuable asset to a college campus, especially in regard to supporting students with chronic health conditions.

In the summer of 2020, Vassar College created a Vassar Together committee to develop plans to reopen campus during the COVID-19 pandemic. The primary focus was to <u>safely</u> return students to an in-person learning and living environment. Protecting and supporting our most at-risk individuals, including our students with chronic health conditions, was of paramount concern. During the committee discussions it became evident that the creation of a case management role was essential to provide Vassar students with support for their health and well-being while transitioning back to campus in the midst of a global pandemic.

Despite the case manager position being a new concept for Vassar College in 2020, the services were so heavily utilized that it became necessary to add a second case manager to the team after only one academic year. In addition to executing their daily roles and responsibilities in the 2020-2021 academic year, the case manager provided on-going services for 7% of our student population, had intensive sessions with 45 students for severe mental health concerns, and assisted 12% of our population in obtaining off-campus COVID vaccines.

Case management duties and responsibilities are varied and extensive. Highlighted below are a few of the services that the case management team offers to Vassar College students:

- Refers and connects students to healthcare resources both on and off campus
- Educates students in self-advocacy
- Supports students in navigating insurance issues
- Assesses needs of students who are struggling academically or socially and develops solutionoriented goals
- Coordinates care for students transitioning between on-campus care and care in their home communities
- Provides emotional support and outreach to students in distress, i.e., psychological, physical, social, or financial
- Collaborates with local hospitals to develop safe discharge plans for students returning to campus after a medical or mental health hospitalization
- Assists students transitioning back to campus after taking a leave of absence

VASSAR COLLEGE

DEPARTMENT OF HEALTH SERVICES

The benefit of a case management position to a college community is immeasurable. The presence of a case manager not only improves and enhances the student's academic and social experience, but it serves as an educational resource in instilling essential life skills. Although all students benefit from these services, having access to a case manager is integral to the success of students with chronic health conditions. These students often require additional, and sometimes specialized, resources and assistance to achieve their academic potential. The case manager can act as a liaison and advocate for the students in so far as they can collaboratively work to identify and access appropriate resources that will facilitate student academic success and future well-being.

Many students with chronic health conditions have time-consuming concerns. These cannot always be effectively addressed in busy college health clinics or counseling centers which is where the role of the case manager becomes crucial. I recently had a medical visit with a student with Type I diabetes. Prior to enrolling in college, their diabetes was well managed under the care of their mother and specialists. Since attending college away from home, they found themselves struggling not only with their glucose control, but with depression and anxiety as well. The challenges this student faced were multi-faceted and they clearly needed specialized care locally, but they were unable to navigate this alone. Thankfully we were able to engage the case manager to personally work with the student and their insurance to successfully establish care with appropriate providers in the community.

In summary, it has become evident that case managers are essential to the wellness of students and the success of Vassar College as an institution. Case managers support students in many dimensions of wellness including physical, emotional, financial, social, intellectual, and occupational. Without this personalized support in place for students in need, the college experience and successful graduation would be compromised. The case manager is also fundamental to cultivating a thriving campus culture focused on equality and inclusivity. By assisting students with accessing services and reducing barriers that might otherwise preclude students from achieving their highest potential, our case management team supports Vassar's mission to create an environment in which all members are valued and empowered to thrive. Vassar College has benefited greatly from the addition of this key team member because a supported student is a successful student!

Thank you for your time and attention to this matter.

Sincerely,

Margot Schinella, FNP

Director of Health Services Vassar College

124 Raymond Ave.

Poughkeepsie, NY 12604

845-437-5802

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I am writing to you as a voter from District 30A. I am also the mother of two young adults with chronic health conditions. They are both graduates of the UMD and faced, for the most part, little support there in terms of their health issues.

As one example, my daughter suffered unpredictable symptomatic flares (headaches, fatigue, pain, fainting, etc.) that occasionally prevented her from attending class. The University offered meager accommodations so she was forced to "beg" her individual professors (unsuccessfully at times) for extensions or to attend class virtually (pre-COVID). She had to repeat one class and was forced to graduate later than planned.

As you may recall, last year your committee and ultimately the Legislature approved the "Task Force on Higher Education— Students with Chronic Health Conditions" to examine how well universities are tracking these students. The work group recommended that each MD university have a case manager dedicated to students with chronic health conditions, many of whom feel "invisible."

My daughter is just one of the thousands of bright and promising students whose college experience could have benefited greatly from having a case manager to support and advocate for them. I ask that you approve this bill so that future "young invisibles" are fully accommodated and included in their higher education. Thank you for your consideration.

Nancy Purdy, District 30A

SB832_iWave_NBhagat_FAV.pdfUploaded by: Natasha Bhagat

Position: FAV



The Honorable Senator Paul Pinsky Education, Health & Environmental Affairs Committee Miller Senate Office Building, 2 West Wing 11 Bladen St., Annapolis, MD 21401

March 1, 2022

RE: SB 832/HB 1098

Dear Chairman Pinsky,

Thank you for this opportunity to provide testimony. I am Natasha Bhagat, a 34-year old who has lived with epilepsy since I was 8. Like my brothers, friends and all my classmates, my life was school. I was a gifted and talented student when I got sick, and that's who I always thought I was. I went to Montgomery Community College and then to American University for almost 10 years. I could only take 1-3 classes a semester because of my health. It was very hard for me to go to college for so long, but it's the only path I knew.

I can't tell you how many times I had to ask for an incomplete or medically withdraw from a class. And even take a semester off for medication changes or hospitalizations. I was very isolated. I never got to live on campus like the other college students.

The only support I received at each college was from Disability Support Services. They gave me some accommodations like extended test time taking, which was of some help, but nothing to help with my chronic condition issues. They told me I had to set up a meeting with each professor individually, preferably before classes started – which was very hard to do – and explain my situation. When professors worked with me, I did very well. When they didn't, I got very stressed and tried to do well in the class – but could not because of my health. This caused so much anxiety that my seizures got worse. Then, I would have to drop it late and lose money and get a bad grade or ask for an incomplete.

I went to the campus health centers but they just referred me to security. I have a medical condition and need health care, but they just wanted my information and made me feel like a security risk. No one ever cared about my physical or mental health and there was no support for students like me. I was so alone.

I tried to do things on campus but always felt like an outsider. I am a second-degree black belt in Tae Kwon Do and am trained to persevere. But, at one point, when I was on medical leave of absence and my mother and I drove by American University, I told her that it made me feel scared. That was a turning point. My mother never knew I felt that way – and maybe I didn't either. We had a long conversation and I finally had to make the very difficult decision to drop out. I was a junior with a 3.5 GPA and had been on the Dean's List. My health has been better but I am at a loss as what to do with my life now.

My entire experience could have been different if I had a case manager to help me navigate college and campus life. I believe passage of this bill can help so many other students with chronic health conditions to succeed in college and not have to give up like I had to do.

Thank you.

Sincerely,

Natasha Bhagat Natasha Bhagat Invisible Wave https://www.invisiblewave.org

SB832.Chronic Conditions.DD Council.Support.pdfUploaded by: Rachel London

Position: FAV



CREATING CHANGE · IMPROVING LIVES

Senate Education, Health, and Environmental Affairs Committee

March 3, 2022

SB 832: Public Institutions of Higher Education – Students with Chronic Health Conditions – Case Manager Position: Support

The Maryland Developmental Disabilities Council (DD Council) is an independent public policy organization that creates change to make it possible for people with developmental disabilities to live the lives they want with the support they need. As such, increasing access to higher education opportunities for people with developmental disabilities, including people with significant disabilities, is one of the DD Council's priorities. The DD Council supports SB 832.

SB 832 promotes inclusion and accountability, and is a critical step to expand access to higher education for individuals with disabilities. It does this by requiring each public institute of higher education designated a case manager that will:

- Coordinate services among different departments;
- Provide information to students about available supports and services;
- ➤ Collect data and information on programs, services, and outcomes.

This is critical because:

- Research shows that receiving a college education and experiencing that exciting time in life is as important for students with disabilities as for those without.
- > Adequate services and supports are essential to academic success.
- ➤ The Individuals with Disabilities Education Act, which provides services and supports for children with disabilities, ages birth to 21, does not provide supports needed in college, such as education coaches, assistive technology, tutors, or natural supports required to learn.
- Individuals with disabilities who attend post-secondary education are more likely to be employed, earning more and requiring less supports.

The time to create access to inclusive higher education opportunities for all students, including those with developmental disabilities in Maryland is now. This is what people with disabilities and their families want – opportunities to continue their education and learn, live, and participate in campus life alongside their peers without disabilities.

Students with disabilities who attend college with the services and supports necessary to succeed not only acquire valuable knowledge, but learn life skills as well, leading to more independence. The designation of a case manager for students is another important step to increase access and opportunity to college experiences for students with disabilities.

Contact: Rachel London, Executive Director: RLondon@md-council.org

¹ January 2012 The Higher Education Opportunity Act: Impact on Students with Disabilities. Madaus, Kowitt, and Laylor.

Testimony In Support of SB 832 - HB 1098 - Higher Uploaded by: Rich Ceruolo

Position: FAV



February 28, 2022

Maryland Senate 11 Bladen St. Annapolis, MD. 21401

<u>In Support of SB 832 / HB 1098</u>: Higher Education – Chronic Health Issues - Case Manager – Support Services

Members of the Maryland Senate's Education, Health, Environment Committee.

We are an organization of military and non-military families with over 1400 plus members fully support SB 832.

We support any bill that improves inclusion and equity in education for persons living with disabilities. I am quite positive that any parent or education stakeholder will have an interest in seeing that legislation is being crafted to help support all of Maryland's citizens. Including those seeking higher learning while trying to make a better life for themselves while working toward independent living.

For those citizens, case managers and on campus support services are as basic a need as eyeglasses for sight, or elevators for those who walking stairs is a challenge. This is about improving engagement and seeing more citizens included in their education and career decisions.

We thank the Delegate and Senator for bringing forward such a positive and transformative piece of legislation. It truly will have a positive impact on all of our citizens and help give them agency in all education decisions in their lives.

We ask that the committee please return a favorable report, and support SB 832.

Thank you all for your time and consideration of our testimony.

Respectfully,

Mr. Richard Ceruolo | richceruolo@gmail.com
Parent, Lead Advocate and Director of Public Policy
Parent Advocacy Consortium (Find us on Facebook/Meta)
https://www.facebook.com/groups/ParentAdvocacyConsortium

SB832_PPC_FAV.pdf Uploaded by: Santi Bhagat Position: FAV

Testimony for Maryland SB 832

Education, Health & Environmental Affairs Committee

March 2, 2022



Working Together to Obtain Quality Health Care for Children & Young Adults with Chronic Conditions & Disabilities

The Honorable Senator Paul Pinsky Chairman Education, Health & Environmental Affairs Committee Miller Senate Office Building, 2 West Wing 11 Bladen St., Annapolis, MD 21401

Thank you, Chairman Pinsky and other esteemed members of the committee for allowing our organization PHYSICIAN-PARENT CAREGIVERS to offer testimony to the Education, Health & Environmental Affairs Committee.

PPC as we are known, is made up of young adults, providers, parents, educators, caregivers, policymakers and other advocates who strongly believe that there can be a better future for the approximately 20 million young adults who live with a chronic condition in the United States. ^{1,2} These brave men and women sometimes refer to themselves as "Young Invisibles" because they might not have an obvious physical issue, but have one or more chronic illnesses such as epilepsy, rheumatoid arthritis, diabetes, anxiety and other diseases. Our organization launched <u>Invisible Wave</u> to create a <u>community that is a safe space</u> and a platform for social change. The types

¹Sarah Schultz, "Don't Be Fooled: Senate Bill is Bad for Millions of Most Vulnerable Young People", Young Invincibles, last modified June 22, 2017. http://younginvincibles.org/press-releases/dont-fooled-senate-bill-bad-millions-vulnerable-young-people/

² Derived estimate of 19.96 million is calculated using the prevalence of 76.2 million 18-34 year olds, 2019 US Census Data, and a prevalence range of 26.2% chronic conditions in 16-17 year olds. "So How Many Millennials Are There in the US, Anyway?" MarketingCharts. September 9, 2019. https://www.marketingcharts.com/featured-30401 and Christina Bethell, et.al. "Optimizing health and health care systems for children with special health care needs using the life course .perspective." Matern Child Health J. 2014 Feb; 18(2): 467–477.

of diseases range from extremely common ones that most of us have heard of to the rarer conditions that only occur in a handful each year. But no matter what the illness, these Young Invisibles bravely try to have as normal a life as possible, trying to do things that most of us take for granted-learn how to drive, take college prep tests, attend courses, enter relationships and have a family. We offer a snapshot into some of the health and education policy related issues that we have witnessed over the years, including the systematic barriers that have decreased the potential productivity for this population. We are here today to ask you to recognize this population and help us work to increase awareness around the health and education needs for millions of teenagers and young adults who have tremendous potential but often fall short due to external factors far beyond their control.

PPC's Health Care Advocacy and Policy Recommendations

PPC has been a convener of major thought leaders in health care to identify barriers to teens and young adults with chronic conditions; we highlight a few of our key findings here:

1. Health care for most individuals, but especially teens and young adults with chronic illnesses is neither patient nor family-centered. Unnecessary silos in care result in poor quality of care, poor transitions and frustrated patients, parents and providers. The current health care system places bright lines between pediatrics and adult medicine, often making any type of transition extremely difficult, time consuming and costly: After the age of 18, almost all pediatric patients, no matter how complex generally are required to transition to providers who have only cared for adults and have only been trained in adult-onset diseases. Even physicians who are trained in both pediatrics and internal medicine often favor an adult practice, with more opportunities to find careers in different parts of the country.

- 2. Lack of information sharing exacerbates issues around quality of care: Much like the division of practices between pediatrics and adult medicine, such a division also exists in the proprietary electronic health records which accompany providers' offices; even doctors within the same health system often can't access pediatric records and vice versa.
- 3. Robust Demographic Info is Deficient for this Population: The nation has made significant investments to study and address the needs of children and adolescents with chronic health conditions through Federal and State Title V programs. These efforts need to be continued to ensure that this population is appropriately studied in young adulthood; unfortunately, young adults with chronic health conditions do not have a home in any Federal, State or local agency. PPC has found that there is little to no population level demographic information on Young Invisibles; as a result we lack understanding around the scope of the issue for Maryland as well as potential solutions. We request Maryland to continue its leadership and invest in studying this population in young adulthood and develop the relevant programs to ensure they maintain optimal health and have the opportunity to succeed in education, work and life.
 - a. The 2009 National Survey of Children with Special Health Care Needs estimates that 19.7% of Maryland 12-17 year olds have special health care needs³, a relatively high prevalence compared to the national prevalence. It is imperative to continue to follow up on this work and know what is happening to this vulnerable population as they grow up and venture into the world on their own. The National Survey's information on insurance, income level, medical homes and impact on ability to work are exactly what needs to be studied in Young Invisibles.

³Data Resource Center for Child & Health Care Needs, "2005/06 vs. 2009/10 National Survey of Children with Special Health Care Needs: Maryland Profile". <u>www.childhealthdata.org</u>

- b. Data on young adults 18-34 years is buried within the larger 18-44 or 18-64 year old population. The Institute of Medicine and National Research Council recommend focusing on young adults as a distinct age group as they are particularly vulnerable and are in a unique developmental life phase; they require specific policies, programs and studies for their age demographic.⁴ Given the inability of the medical system to provide age appropriate care to Young Invisibles, it is critical to analyze the utilization, cost and outcomes of 18-34 year olds.
- c. Access to primary care, specialists and other providers needs to be studied. Social determinants need to be elucidated and included in the system of care for this vulnerable population.

PPC's Education Advocacy and Policy Recommendations

The educational systems, both lower and higher, likewise present barriers to achieving the productive lives that Young Invisibles deserve; the following is a snapshot of some our findings, again in work with experts and thought leaders in the education community.

Education is critical to young adults with chronic conditions for health literacy and decision-making, and education enables more stable and higher-paying careers.

These young adults cannot afford to be uneducated and risk being placed on social welfare especially given their higher medical bills and risk for medical bankruptcy.

A fundamental misconception is that young people with chronic conditions can be adequately educated through existing policies and programs for disabilities, e.g., IDEA, ADA. Such laws provide accommodations designed for people with disabilities,

⁴ Committee on Improving the Health, Safety, and Well-Being of Young Adults; Board on Children, Youth, and Families; Institute of Medicine; National Research Council; Bonnie RJ, Stroud C, Breiner H, editors. Investing in the Health and Well-Being of Young Adults. Washington (DC): National Academies Press (US); 2015 Jan 27. 2, Young Adults in the 21st Century. https://www.ncbi.nlm.nih.gov/books/NBK284782/

i.e., mobility, learning, intellectual, developmental, vision and hearing. They are not designed to address the specific needs for chronic health conditions. **Chronic health conditions differ from other disabilities**. Chronic health conditions are episodic, unpredictable and wax and wane. Health exacerbations, medical appointments, hospitalizations and treatment regimens may impact attendance and performance.

Young Invisibles need chronic care management, and, in parallel, they need ongoing flexible chronic care educational accommodations, services and supports, e.g., videoconferencing into class when they are not well enough to attend, recordings when they cannot videoconference, advisors familiar with chronic health issues, tutors, adapted workloads, peer support, internships.⁵ The growing numbers of students with chronic health conditions attending college underscore the need to understand better what services they are or are not getting and how they are faring.

Forty percent of college students drop out or withdraw for a period of time.⁶ It is imperative to understand how many of these students struggle because of chronic health conditions. America needs every student who has the desire and ability to be educated to complete college and join the national workforce. Our key recommendations include:

1. **Case Management:** Increased Awareness and Supportive Resources around Young Invisibles at Institutions of Higher Education. Case managers would provide a critical first support for Young Invisibles to help them navigate the resources available in college. These students may have specific needs for education, dorm living, dining, career preparation, internships and campus

⁵National Collaborative on Workforce and Disability, "<u>Transition's Missing Link: Health Care Transition"</u>, September 2012.

⁶Bill & Melinda Gates Foundation. "What We Do: Post-Secondary Success", https://www.gatesfoundation.org/What-We-Do/US-Program/Postsecondary-Success

life, and a case manager could help them get the support they need so they can succeed.

- 2. Health Case Management. Many conditions are invisible, and, when under control, the student may feel and/or appear healthy. As a result, professors may expect them to perform like their healthy peers. When these students prioritize education or work over health management behaviors, health flares may occur, further impacting attendance and performance at school or work. These students need medical care and training for health selfmanagement. College health centers could facilitate such services through health case managers.
- 3. When well, it is important for students with chronic conditions to attend class and interact with the professors and other students. However, when their conditions flare, they need support to enable them to keep up and finish their assignments. They need specialized counselors who understand the issues particular to young adults with chronic conditions, and who can help them interface with professors and other professionals and provide guidance as to available supports. They need living and learning communities that support their issues. They need professors and deans who understand that they need accommodations and supports for their absences and illnesses. One such exemplar model is The DePaul Chronic Illness Initiative which provides faculty and advisors to help students with chronic health conditions navigate the system, advocate for them and provide support so they can succeed.⁷

⁷Royster, Lynn, and Olena Marshal, "Chronic Illness Initiative: Supporting College Students with Chronic Illness Needs at DePaul University", *Journal of Postsecondary Education and Disability*, 2008. https://files.eric.ed.gov/fulltext/EJ825778.pdf

4. Collection of Important Demographic Data around Young Invisibles in Education: To fully grasp the scope of Young Invisibles' issues, Maryland needs to collect data on their health status and academic outcomes. This is in line with the efforts at the Bill and Melinda Gates Foundation⁸ and the Higher Education Reauthorization Act in Congress⁹; both efforts call for additional data collection on all students and programs to serve the neediest. The Institute for Higher Education Policy has a blueprint for a Federal Postsecondary Student-Level Data Network to collect data to inform governmental and institutional policies and aid in student success. ¹⁰

The Center on Young Adult Health and Development, School of Public Health, University of Maryland is equipped to conduct the data analysis on Maryland college students; they have already conducted the largest national, longitudinal *College Life Study*. Preliminary data from this NIH sponsored study reveals that preliminary data suggests that a wide variety of chronic physical and mental health conditions exist in young adults in the Mid-Atlantic region. Further research is needed to clarify the prevalence and nature of those conditions, e.g., the diagnosis, severity, chronicity.¹¹

5. Foster Innovative Learning Models to Deal with Critical Issues Facing Young Invisibles: Innovative learning models are critical to this population because of illness and attendance issues. These students need hybrid classrooms so they have the social experience of attending class but also access to teleconferencing, recorded lectures, note takers, tutors, adapted workloads, flexible deadlines, extended time for exams and assignments, peer support, and internships. Technology can be leveraged to help students with

⁸Ibid

⁹ Doug Sword, "Higher Education Bill Expected in Senate Soon", *Roll Call*, January 26, 2018.

¹⁰Robertson, Amanda, Jamey Rorison, and Mamie Voight, "A Blueprint For Better Information: Recommendations For a Federal Postsecondary Student-Level Data Network" Institute for Higher Education Policy, October 2017.

 $^{^{11}}$ Amelia Arria (center director) in discussion with the author, February 24, 2020.

attendance, as evidenced by the double-robots that Anne Arundel County is using to help hospitalized and home-bound students participate in class and be with their friends.¹²

- 4. Another viable option for our student population is a combined in class/virtual/ online program with flexible deadlines. One example of the online piece is University of Wisconsin's Flexible Option Model. ¹³
- 5. The Maryland Higher Education Commission's recommendations for college programs for students with intellectual and developmental disabilities could be adapted for Young Invisibles. In addition to the Commission's recommendation for data collection to measure the impact on the academic and social outcomes of students, it recommends internships, student centered academic advising, multiple academic supports, peer mentoring and numerous other supports. ¹⁴

In conclusion, we thank the Committee for your time and consideration; we acknowledge that resources are scarce but we are confident that by building minimally on existing investments, we can effectively leverage the ability of millions of young adults, thousands in the state of Maryland to be healthier and more productive.

¹²Theo Hayes, "Anne Arundel County Schools Bring Robots to Hospitalized Students", WBAL TV, October 24, 2017.

¹³Doug Sword, "Higher Education Bill Expected in Senate Soon", *Roll Call*, January 26, 2018. https://www.rollcall.com/news/policy/higher-education-bill-expected-senate-soon

¹⁴Maryland Higher Education Commission, "Task Force for Expanding Credit and Noncredit Courses for Students with Intellectual and Developmental Disabilities", January 2016. http://www.mhec.state.md.us/publications/Documents/AcademicAffairs/IDDFinalDraft.pdf

SB832_SantiBhagat_FAV.pdf Uploaded by: Santi Bhagat Position: FAV



Working Together to Obtain Quality Health Care for Children & Young Adults with Chronic Conditions & Disabilities

The Honorable Senator Paul Pinsky Education, Health & Environmental Affairs Committee Miller Senate Office Building, 2 West Wing 11 Bladen St., Annapolis, MD 21401

March 1, 2022

RE: SB 832/HB 1098

Dear Chairman Pinsky,

I am Santi Bhagat, a physician and mother of a young adult who grew up with a chronic health condition. I founded <u>Physician-Parent Caregivers</u>, a voluntary non-profit dedicated to quality health care and quality of life for an estimated 20 million young Americans with chronic conditions. Historically overlooked and ignored, they call themselves Young Invisibles (Yi). Last year, we launched a young adult movement called <u>Invisible Wave</u> that advocates for their health and civil rights.

You may be wondering why this population is invisible and overlooked. Advances in medicine and technology now enable over 90% of teens with chronic conditions to survive into adulthood. It is a miracle the world did not expect. As a result, adult medicine, higher education, government and society at large did not prepare to receive these young people. And they exist now in every community. At least 1 in 4 young adults grows up with a childhood condition and many more develop them in young adulthood.

In 2018, former delegate Aruna Miller introduced the <u>first bill to study Yi</u> and it passed the House of Delegates unanimously. Time precluded a vote in the senate. In 2021, Senator Brian Feldman and Delegate Joseline Pena-Melnyk <u>reintroduced this bill;</u> language was passed through the budget. The workgroup met over the summer and I had the opportunity to participate with three Young Invisibles. The workgroup made a number of recommendations in their <u>report</u>, including a case manager and a health case manager for Yi in college.

We are thankful to Delegate Pena-Melnyk and Senator Feldman for introducing this bill on college case management for students with chronic health conditions. It is a monumental first step to provide much needed support for this neglected population.

My non-profit Physician-Parent Caregivers works in Maryland and at the national level. Our policy committee organized a national policy working group that has strong representation from higher education, including The American College Health Association and The Association on Higher Education and Disability. Both are interested in our work in Maryland and this bill. Another member, Margot Schinella, Vassar College, is submitting testimony to support this bill, citing Vassar's success with case management to help their students with chronic conditions.

Our national working group and the members at last year's Maryland Workgroup are stating that they are seeing a shift in the profile of students accessing disability support services. In the past, most students had mobility, visual, hearing and learning disabilities. Today, students with chronic conditions comprise the first or second largest groups.

The fiscal policy note for the 2021 bill highlighted that the University System of Maryland does not have any policies on accommodations specific to students with chronic health conditions. This is a critical finding: disability accommodations are presumed to address the academic needs of these young people. But chronic conditions are episodic and unpredictable. Yes, it's difficult for professors to accommodate, but I can assure you that none of us can imagine how difficult it is for Young Invisibles.

Colleges need to identify, track and support their students with chronic conditions. They need to have policies, programs and services to ensure their students stay in good health, learn and grow. Since data are lacking on the prevalence, supports and outcomes, we are in the dark. In the face of this Covid pandemic, how are colleges informing and protecting their students with chronic conditions?

Covid-19 is highlighting disparities that Young Invisibles face. An analysis shows they are at extremely high risk of Covid related deaths—13 times higher than their healthy peers. Senator Chris Van Hollen and Judy Woodruff spoke at our summit in December 2020 on the urgent need to address Young Invisibles. The senator has written two letters to the CDC asking them to assess the risk designation and to prioritize them for vaccinations. He is most concerned about college students with chronic conditions.

College health centers can play a major role in helping Yi. I'd like to refer to two articles about college health centers. The first is a <u>Washington Post investigative report</u> that was prompted by Olivia Peregol's death at the University of Maryland. This report shows that many colleges have numerous incidents of morbidity and mortality when students experience acute or chronic illnesses. Another is an article in the <u>Journal of Pediatrics</u> that says most college health centers are capable of providing primary care for students with chronic conditions. Clearly, this is an urgent unmet need that is affecting millions of students across the country.

Just like other students, Young Invisibles are in a vulnerable life phase. Many supports could be in place to help them stay on track and graduate, but they are not, so these students often suffer, get poor grades or drop out.

<u>Bill Gates has pointed out that the US has an extremely high dropout</u> - 45% of students drop out or withdraw for a period of time. We need to know how many of these students have chronic health conditions. College graduates earn as much as 65% more than high school graduates and this is so important for Young Invisibles who have exorbitant medical bills and are at high risk for medical bankruptcy that can ruin their lives.

Education is also the most important factor in being able to make sound health care decisions, an undeniable need for Young Invisibles.

We must confront the critical 21st century issue of young adult health. We need to address this population as a single age demographic that has common needs -- not by physical or mental health conditions, and not by a specific condition.

This is not just about health and educational equity; we have a moral imperative to treat Young Invisibles as equal to everyone else and give them the opportunity to be in optimal health and succeed in Higher Education. But this is not happening. Students with chronic physical health conditions are not included in higher education policies that include programs, assistance and data for mental health, disabilities and intellectual disabilities. It's time we correct these tragic oversights and this ongoing negligence.

Thank you for considering this landmark bill. We believe that Maryland is the first state legislature to support students with chronic conditions in higher education. Passing it would position Maryland as a leader for the next generation's health, well-being and participation in society.

Sincerely,

Santi KM Bhagat, MD, MPH Founder, Physician-Parent Caregivers Creator, Invisible Wave Movement

Morgan State Response - SB0832.pdfUploaded by: Stacey Benn

Position: FWA



Office of the President

Morgan State University Testimony Dr. David Wilson, President

Senate Bill 0832 (Senator Feldman) / House Bill 1098 (Delegate Pena-Melnyk)

Public Institutions of Higher Education – Students With Chronic Health Conditions –

Case Manager

Committee: Education, Health, and Environmental Affairs

March 2, 2022

Favorable With Amendments

Chair Pinsky, Vice Chair Kagan, and members of the Education, Health, and Environmental Affairs Committee. We, at Morgan, thank you for the opportunity to share our position on Senate Bill 0832. The summary of the Bill states the following: Requiring each public institution of higher education to designate a case manager for students with chronic health conditions; and specifying the duties of the case manager.

Morgan State University is the premier public urban research university in Maryland, known for its excellence in teaching, intensive research, effective public service and community engagement. Morgan prepares diverse and competitive graduates for success in a global interdependent society.

Over the decades, Morgan State University has made student success a top priority, to include the health and well-being of the campus community. For example, in our 2021-2030 strategic plan, our number 1 goal is to "Enhance Student Success and Well-Being." Along with our student success component, Morgan considers students holistically which include physical and mental well-being. With that said, we provide for the well-being of students through the University Health Center, University Counseling Center, Office of Retention, and Disabilities Office. In additional, the Morgan Campus Health Monitoring and Response Team (MCHMRT) was added during the pandemic, to track and respond to testing protocols. Morgan works quite assiduously to ensure that we assist students financially as our resources will allow.

Morgan State University supports SB0832 in spirit. We offer one major caveat: we would offer full support of the Bill if the Legislature would further amend it to provide Universities with funding for the cost of a new employee to fill the case manager position.

Without amendments, like the one we suggest, the Bill would increase the University's budget costs.

We appreciate the opportunity to work with the State in reaching a solution to support our students as we continue to grow the future and lead the world.

SB832_USM_UNF_Boughman - 3.2.22.pdfUploaded by: Joann Boughman

Position: UNF



SENATE EDUCATION, HEALTH, AND ENVIRONMENTAL AFFAIRS COMMITTEE Senate Bill 832

Public Institutions of Higher Education – Students with Chronic Health Conditions –

Case Manager

March 2, 2022

Joann Boughman, Senior Vice Chancellor for Academic and Student Affairs Unfavorable

Chair Pinsky, Vice Chair Kagan and committee members, thank you for the opportunity to share our thoughts on Senate Bill 832. The bill requires public institutions of higher education to hire case managers to coordinate services for students with chronic health conditions, provide information to students regarding the access to supports and services, and collect and report a significant amount of information on these students.

Students with chronic health conditions that identify themselves to appropriate campus officials deserve support. Information about the availability of services is readily available to students under the federal Americans with Disabilities Act (ADA). Adding a unit of required professional personnel would be a financial challenge to some of our campuses.

Senate Bill 832 presents several challenges for implementation because the definition of chronic health condition is vague and would require health experts to certify if a student had a chronic condition in need of ongoing medical attention. The bill confounds medical treatment with certain support services, and each campus has a different level of capability to provide those medical services that might be necessary. The case manager, as defined in this bill, implies the need for a medical professional. The language requires sharing of data among medical and non-medical units which is problematic, as all medical information is protected under Health Insurance Portability and Accountability Act of 1996 (HIPAA). Medical units would not want to receive medical information for students who are not their patients, and the sharing of this personal information outside of the medical treatment unit could be problematic. Concern has been expressed about the health and medical privacy of University System of Maryland (USM) students if Senate Bill 832 were law.

The reporting that is required is extensive and implies the ability to measure quality and effectiveness without definition. The reporting of these outcomes on students who are patients in a health center is qualitatively different than reporting aggregated outcomes from the ADA/Disability Services office for students who have identified themselves as requiring support services. Because of the structure of campus student services, there may be important ways that collection of data across departments becomes complicated and may not be possible while complying with HIPAA rules. For example, career services offices work very differently than academic counseling or housing and dining arrangements, and these offices do not depend on HIPAA protected private information.

Our expectation is that students who require support services would report to the Office of Disability Services, where coordination of services and follow up take place. This would include students with "invisible" chronic health conditions as well as other disabilities. USM campuses will continues to improve the notification and messaging of the availability of support services. Additionally, USM's Vice Presidents for Student Affairs work closely with their ADA/Disabilities Office and their Health Center Director to improve the follow up of students who have conditions requiring additional support and service.

The continuing safety, health and success of students is the top priority. The USM acknowledges that there are students who may need more information and encouragement to seek the many support services available on our campuses.

However, the USM respectfully requests an unfavorable report on Senate Bill 832.



































About the University System of Maryland

The University System of Maryland (USM)—one system made up of 12 institutions, three regional centers, and a central office—awards 8 out of every 10 bachelor's degrees in the State of Maryland. The USM is governed by a Board of Regents, comprised of 21 members from diverse professional and personal backgrounds. The chancellor, Dr. Jay Perman, oversees and manages the operations of USM. However, each constituent institution is run by its own president who has authority over that university. Each of USM's 12 institutions has a distinct and unique approach to the mission of educating students and promoting the economic, intellectual, and cultural growth of its surrounding community. These institutions are located throughout the state, from western Maryland to the Eastern Shore, with the flagship campus in the Washington suburbs. The USM includes Historically Black Colleges and Universities, comprehensive institutions, research universities, and the country's largest public online institution.

SB0832 oppose.pdfUploaded by: Peggy Williams Position: UNF

SB0832 - OPPOSE

As a college student, even though I was over 18, I was still very much dependent on my parents. As a parent, I imagine my kids will still be somewhat dependent on me in college, and my responsibility and under my care essentially. So the thought of some medical case manager coaxing or pressuring my college-age child/student to take some intervention without my knowledge, i.e., an unnecessary or potentially harmful flu shot if they have asthma for instance, or collecting health or medical data on my kid is unacceptable. Please oppose SB0832.

Thank you

Peggy Williams Severna Park, MD D33

SB 832 Students With Chronic Health Conditions - C

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Position: INFO



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Senate Bill 832 Public Institutions of Higher Education - Students With Chronic Health Conditions - Case Manager Senate Education, Health, and Environmental Affairs Committee

Senate Education, Health, and Environmental Affairs Committee
March 2, 2022

Letter of Information

Chair Pinsky, Vice Chair Kagan, and Members of the Committee,

Thank you for the opportunity to share our thoughts on Senate Bill 832 - Public Institutions of Higher Education - Students With Chronic Health Conditions - Case Manager, which requires public institution of higher education to designate a case manager for students with chronic health conditions.

St. Mary's College of Maryland is committed to providing its students with a premier liberal arts education that is accessible to all. To support that commitment, the College's Office of Student Success Services, comprised of staff who provide students with support and service assistance, works with students on an individual basis to support their specific needs. The requirements to provide a case manager as required by the Bill would require at a minimum one additional position at a cost of approximately \$55K plus benefits. The precise number would depend on the number of cases an individual case manager is reasonably expected to monitor.

Thank you for your consideration and continued support of St. Mary's College of Maryland.

Tuajuanda C. Jordan, Ph.D.

President













