

**HB1098\_InvisibleWave\_DrAnupamSidhu\_FAV.pdf**

Uploaded by: Anupam Sidhu

Position: FAV

Dear Chairwoman McIntosh,

I am Anupam Sidhu and I ask you to support this bill favorably.

In the United States, per [cdc.gov](http://cdc.gov), more than 40% of school-aged children and adolescents have at least one chronic health condition,<sup>1</sup> such as asthma, obesity, other physical conditions, and behavior/learning problems. Meanwhile, 60% of adults are said to have at least 1 chronic illness.

A chronic condition “is a physical or mental health condition that lasts more than one year and causes functional restrictions or requires ongoing monitoring or treatment” [1,2]. Chronic diseases are among t

A recent Milken Institute analysis determined that treatment of the seven most common chronic diseases coupled with productivity losses will cost the U.S. economy more than \$1 trillion dollars annually.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5876976/>

I have the unique position of being Physician and an adult with multiple chronic conditions that began in childhood.

As a child, I was considered ‘lazy’ as I had little energy to run, jump or play. I rarely played sports, by 4<sup>th</sup> grade could not run a mile, climbing stairs was often exhausting and I would have days where I felt competently exhausted upon waking up. Somehow, I managed to keep up with school. I would intentionally work harder on my ‘good days’ so I could coast on my ‘bad days’.

Things became harder when I was in Medical School, where every day and every class is crucial. Still, I managed to keep up, graduated, finished a competitive Family Medicine Residency and have now been practicing for nearly 13 years.

I wasn’t given my first diagnosis until I was 23, when I was already halfway through medical school. Then in Residency, I was diagnosed with Idiopathic Chronic Angioedema. 6 years later I was diagnosed with a food sensitivity that, in hindsight combined with my Angioedema had likely caused many of my symptoms since childhood.

During school, because I was undiagnosed, I coped by telling myself I was lazy, and I need to work harder. I didn’t know there were actual medical reasons for why I couldn’t function like my peers. Yet, I managed to keep up and felt I did well, considering. I feel my success is directly linked to my significant support system in my friends and family. Financially, my parents were able to support me through school, so I didn’t have to juggle work and school.

Sometimes, I think, if I could have done this with undiagnosed, untreated chronic conditions with no assistance or accommodations from my school, imagine what else I could have done with a little extra help during my flares. My test scores were always lower during flares. Fortunately, I would do well enough to average well when I was feeling well.

However, I understand many of my Chronic Illness Warrior friends have chronic illnesses that often render them unable to perform in school at times. Meeting deadlines when you've just recovered from an unexpected seizure or Multiple Sclerosis flare may be physically impossible.

Having a Case Manager to help navigate these unique challenges could be incredibly impactful.

As a physician, I see many of my intelligent, determined and ambitious patients crave purposeful education and careers. Many of these young patients end up leaving school due to not being able to juggle work and school while also managing their chronic condition. Often, after missing too many classes or assignments, they must drop classes or quit school completely. They don't choose to stay home; they are forced to stay home because the society we live in has not made space for their unique set of needs. I see the light and excitement in their eyes slowly fade as their ambition turns into practicality and defeat. It's heartbreaking.

Pediatric patients have access to assistance from parents, school counselors and care coordinators.

In the hospital, case managers effectively improve care coordination, therefore reducing hospital length and preventing readmissions.

Medicare patients often have access to Case Managers who help coordinate social services, home health, physical therapy, medication refills and follow up appointments.

There is a clear void of assistance for young adults who are leaving pediatric services but not yet qualifying for Medicare Services.

Areas I see Case Managers assisting College age Chronic Illness students would be:

Assisting with determining an appropriate education plan based on abilities, appropriate housing based on physical functions, navigating financial aid and communication with educators for necessary accommodations. With these additional tools, in the long term, I believe society would benefit from the investment in these young adults.

I deeply appreciate you taking the time to listen to my story.

Before I met Invisible Wave Movement, I had never even considered that I deserved additional support based on the obstacles brought on by my chronic illnesses. I believed it was solely my problem to figure out and handle on my own. It was lonely and difficult. With this new bill, I less lonely and hopefully easier for these ambitious young adults.

I sincerely hope you will consider passing this legislation to help support Chronic Illness young. I want them to know they deserve support and that we support their efforts in achieving meaningful contributions to our society.

Thank you,

Anupam Sidhu M.D.

# **HB 1098 Students w Chronic Conditions SPONSOR Pena**

Uploaded by: Joseline Peña-Melnyk

Position: FAV

**JOSELINE A. PEÑA-MELNYK**

*Legislative District 21*  
Prince George's and  
Anne Arundel Counties

---

*Vice Chair*

Health and Government  
Operations Committee

*Subcommittees*

Insurance and Pharmaceuticals

Chair, Public Health and  
Minority Health Disparities



## *The Maryland House of Delegates*

ANNAPOLIS, MARYLAND 21401

*Annapolis Office*

The Maryland House of Delegates  
6 Bladen Street, Room 241  
Annapolis, Maryland 21401  
410-841-3502 · 301-858-3502  
800-492-7122 Ext. 3502  
Joseline.Pena.Melnyk@house.state.md.us

---

*District Office*

P. O. Box 1251  
College Park, Maryland 20741-1251

March 8, 2022

### **HB 1098 - Public Institutions of Higher Education – Students With Chronic Health Conditions – Case Manager**

#### **Testimony of Delegate Joseline A. Peña-Melnyk (FAV)**

Chair McIntosh, Vice Chair Chang, and members of the Appropriations Committee, I am pleased to present House Bill (HB) 1098. This bill requires each public institution of higher education to designate a case manager for students with chronic health conditions.

For children with chronic health conditions, the support they rely upon in their formative years of kindergarten through 12th grade evaporates once they graduate from high school and pursue higher education. Managing chronic care is challenging and many individuals with chronic conditions are often overlooked or ignored. We need to ensure that students are able to complete their education while having their needs met.

Last year, the Maryland Higher Education Commission (MHEC) and the Maryland Department of Health (MDH) established a workgroup to examine the data available on students with chronic health conditions attending institutions of higher education in the State. The workgroup provided recommendations to eliminate challenges and accommodate the needs of students with chronic health conditions. One of those recommendations is the basis of this bill - "support campuses to employ centralized "case managers" for students to coordinate services among different departments (e.g., faculty, health centers, medical professionals, etc.)."<sup>1</sup>

The report states that "there are a number of resources campuses in Maryland may provide to students with chronic health conditions."<sup>2</sup> This bill would require each institute of higher education in Maryland to provide case management services to utilize these existing resources. Case managers would help these students with chronic conditions by coordinating preventions, interventions, and support efforts across campus and community systems to

---

<sup>1</sup> [http://dlslibrary.state.md.us/publications/JCR/2021/2021\\_197b.pdf](http://dlslibrary.state.md.us/publications/JCR/2021/2021_197b.pdf), page 17

<sup>2</sup> [http://dlslibrary.state.md.us/publications/JCR/2021/2021\\_197b.pdf](http://dlslibrary.state.md.us/publications/JCR/2021/2021_197b.pdf), page 13

reduce barriers that impede academic success. They would serve as a coordinator of existing services and a liaison to communicate with other campus staff and organizations.

The case manager would also collect data and information on currently available programs, services, and outcomes. This would serve to enhance and continue data collections on students with chronic health conditions, another recommendation of the report.<sup>3</sup>

The purpose of this bill is not to reinvent the wheel or cause an inconvenience to our institutions of higher education. Student case management programs already exist at the University of Baltimore and Johns Hopkins University.<sup>4</sup> Loyola recently implemented case management services to support residential students that test positive for COVID-19.<sup>5</sup> Goucher College utilizes clinical case management to help students locate community mental health care services during the summer.<sup>6</sup> UMBC has Academic Advocates who follow a coordinated care case management model that facilitates support to undergraduate students.<sup>7</sup> These services already successfully exist in some institutions of higher education, providing a blueprint for others to follow. Case management is an easy and effective recommendation suggested by the Maryland Higher Education Commission (MHEC) and the Maryland Department of Health (MDH) to support students with chronic conditions.

This bill is the first step in ensuring that every child in our state grows up with the opportunity to reach their dreams and aspirations. Young adulthood is the time for those dreams to come to fruition. We owe it to this often-overlooked population of students to give them support and help while they seek their academic goals.

Thank you for the opportunity to present House Bill 1098. I respectfully request a favorable report.

---

<sup>3</sup> [http://dlslibrary.state.md.us/publications/JCR/2021/2021\\_197b.pdf](http://dlslibrary.state.md.us/publications/JCR/2021/2021_197b.pdf), page 9

<sup>4</sup> <http://www.ubalt.edu/about-ub/offices-and-services/dean-of-students/compass/>

<sup>5</sup> <https://www.loyola.edu/about/coronavirus-update/campus-plan/health-safety/case-management>

<sup>6</sup> <https://www.goucher.edu/experience/living-well/student-counseling-center/case-management>

<sup>7</sup> <https://academicsuccess.umbc.edu/coordinated-care/>

# **HB1098 Testimony.pdf**

Uploaded by: Maryland Legislative Latino Caucus

Position: FAV



## MARYLAND LEGISLATIVE LATINO CAUCUS

Lowe House Office Building, 6 Bladen Street, Room 200 · Annapolis, Maryland 21401  
Phone 410-841-3374 | 301-858-3374 · 800-492-7122 Ext. 3374 · Fax 410-841-3342 | 301-858-3342  
latino.caucus@house.state.md.us · www.mdlatinocaucus.org

DAVID FRASER-HIDALGO, CHAIR  
JOSELINE A. PEÑA-MELNYK, VICE-CHAIR  
GABRIEL ACEVERO, TREASURER  
JESSE T. PIPPY, SECRETARY  
MADELIN MARTINEZ, EXECUTIVE DIRECTOR

**SENATORS**  
MALCOLM AUGUSTINE  
PAMELA G. BEIDLE  
JILL P. CARTER  
GUY GUZZONE  
SHELLY HETTLEMAN  
CHERYL C. KAGAN  
BENJAMIN F. KRAMER  
SUSAN C. LEE  
JIM ROSAPEPE  
WILLIAM C. SMITH, JR.  
JEFF WALDSTREICHER  
MARY L. WASHINGTON, PH.D.  
RONALD N. YOUNG  
CRAIG J. ZUCKER

**DELEGATES**  
HEATHER BAGNALL  
BEN BARNES  
J. SANDY BARTLETT  
LISA BELCASTRO  
REGINA T. BOYCE  
AL CARR  
LORIG CHARKOUDIAN  
CHARLOTTE CRUTCHFIELD  
BONNIE CULLISON  
JESSICA FELDMARK  
DIANA M. FENNELL  
WANIKA B. FISHER, ESQ.  
LINDA FOLEY  
CATHI FORBES  
JIM GILCHRIST  
ANNE HEALEY  
SHANEKA HENSON  
TERRI L. HILL, M.D.  
JULIAN IVEY  
DANA JONES  
ARIANA KELLY  
KENNETH P. KERR, ED.D  
MARC KORMAN  
CAROL L. KRIMM  
MARY A. LEHMAN  
JAZZ LEWIS  
ROBBYN LEWIS  
BROOKE E. LIERMAN  
LESLEY J. LOPEZ  
SARA N. LOVE  
ERIC LUEDTKE  
MAGGIE MCINTOSH  
DAVID MOON  
JULIE PALAKOVICH CARR  
SHANE PENDERGRASS  
LILY QI  
PAMELA E. QUEEN  
MIKE ROGERS  
SHEILA RUTH  
EMILY SHETTY  
STEPHANIE SMITH  
JARED SOLOMON  
VAUGHN STEWART  
JEN TERRASA  
GERALDINE VALENTINO-SMITH  
ALONZO T. WASHINGTON  
MELISSA WELLS  
NICOLE A. WILLIAMS, ESQ.  
KAREN LEWIS YOUNG

TO: Delegate Maggie McIntosh, Chair  
Delegate Mark S. Chang, Vice Chair  
Appropriations Committee Members  
FROM: Maryland Legislative Latino Caucus (MLLC)  
DATE: 3/4/2022  
RE: HB1098 Public Institutions of Higher Education - Students With  
Chronic Health Conditions - Case Manager

### **The MLLC supports HB1098 Public Institutions of Higher Education - Students With Chronic Health Conditions - Case Manager**

The MLLC is a bipartisan group of Senators and Delegates committed to supporting legislation that improves the lives of Latinos throughout our state. The MLLC is a crucial voice in the development of public policy that uplifts the Latino community and benefits the state of Maryland. Thank you for allowing us the opportunity to express our support of HB1098.

The size and rapid growth of the Latino population offers considerable reason to focus on chronic conditions.<sup>1</sup> In 2019, there were 176,838 Hispanic Youth enrolled in Maryland public schools.<sup>2</sup> Any number of these students could be living with a chronic condition. Grade schools and high schools provide amazing support for students with chronic conditions. This bill would require each institute of higher education in Maryland - including public and community colleges to provide case management services for students with chronic conditions.

Case managers would help these students by coordinating preventions, interventions, and support efforts across campus and community systems to reduce barriers that impede success. On average, College graduates earn as much as 65% more than high school graduates. It is critically important that these students receive the support they need to graduate. Education is the most important factor in being able to make sound health care decisions, which is an undeniable need for this population. Latino College students living with chronic health conditions deserve every opportunity to succeed academically while navigating life with a chronic condition.

For these reasons, the Maryland Legislative Latino Caucus respectfully requests a favorable report on HB0039.

<sup>1</sup> Gretchen Livingston, Susan Minushkin, and D'Vera Cohn, "II. Hispanics and Chronic Disease in the U.S.," Pew Research Center's Hispanic Trends Project, <https://www.pewresearch.org/hispanic/2008/08/13/ii-hispanics-and-chronic-disease-in-the-u-s/>.

<sup>2</sup> Maryland State Department of Education, "Maryland Public School Enrollment by Race/Ethnicity and Gender and Number of Schools" (Maryland State Department of Education, September 30, 2019), [https://p3cdn4static.sharpschool.com/UserFiles/Servers/Server\\_9046340/File/MSDE%209.30.2019%20Official%20Enrollment.pdf](https://p3cdn4static.sharpschool.com/UserFiles/Servers/Server_9046340/File/MSDE%209.30.2019%20Official%20Enrollment.pdf).



**Scan03042022.pdf**

Uploaded by: Nancy Purdy

Position: FAV

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. Clearly, the system as it stands, failed her.

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, among other things, 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. Student athletes at UMD are afforded dedicated counselors to ensure they graduate; it's time that students like my daughter are provided similar support.

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

**HB1098\_iWave\_NBhagat\_FAV.pdf**

Uploaded by: Natasha Bhagat

Position: FAV



The Honorable Chairwoman Maggie McIntosh  
Appropriations Committee  
House Office Building  
6 Bladen St., Annapolis, MD 21401

March 4, 2022

RE: HB 1098/ SB 832

Dear Chairwoman McIntosh,

Thank you for this opportunity to provide testimony. I am Natasha Bhagat. I have lived with epilepsy since I was 8 years old. Like my brothers, friends and 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 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>

**HB1098\_InvisibleWave\_NicholasPrastos\_FAV.pdf**

Uploaded by: Nicholas Prastos

Position: FAV

Dear Chairwoman McIntosh,

I am Nicholas Prastos and I ask you to support this bill favorably. As a chronically ill patient resulting from Long Covid, I strongly believe these services are overdue and going to be especially needed after this pandemic. Estimates are predicting that between 10-30% of Covid patients will come down with some form of long covid. I personally have been unable to attend class (a masters program at New York University) because a system has not been set up to accommodate chronically ill students like me. It is unfortunate that with the proliferation of remote work and remote study we still have impediments when it comes to the academic system's ability to support the chronically ill. I believe reform and support is not only doable, it will be more affordable than would be in the past due to technology's influence on institutions and their students.

A higher education system that supports its chronically ill students with dedicated counselors to help us navigate our way through the learning and collegiate integration process in congruence with appropriate job assistance will be greatly beneficial to the students as well as society at large.

Thank you for listening.

Regards,

Nicholas Prastos

# **HB59-Firmin-Testimony.pdf**

Uploaded by: Patricia Firmin

Position: FAV



Secondary education is an invaluable tool for success. Unfortunately for many students with a chronic illness, the tool can be very challenging to thrive. College is a fast-paced, unique environment with little room for error. The stress of the schooling can exacerbate and even cause chronic illness. While some professors are accommodating, there are times when my professors were a hindrance. College is not “like the real world.” A case manager would potentially improve the schooling of many deserving students with unequal footing.

My name is Patricia Firmin and I attended the University of Maryland College Park. I received a bachelor’s degree in Chemical Engineering in 2018, three years later than my peers. By that point I was working full time. My chronic illness actually improved while starting my career. I am able to balance my abilities and needs with typical sick days and slow days on par with my co-workers. I am able to take FMLA when needed. The slower pace of “real world” has improved my invisible disability.

I have an official diagnosis of Fibromyalgia, although my symptoms match exactly with that of two rare auto-immune nerve disorders that my father suffers from. My symptoms include joint pain, extreme muscle weakness, dizziness, chills, and numbness. On my worst mornings, my energy level is so low that I have to decide whether to eat breakfast or brush my teeth. When my symptoms are especially bad and long-lasting, depression hits.

I did have official accommodations with the university through the DSS which was beneficial, but it only went so far. I missed mandatory attendance labs one-too-many times. My peers would rate me lower on group projects due to my absence in labs and meetings. When I had difficulty walking, the bus that I could schedule to bring me to classes would be overbooked, making it useless when my condition flared. Prior to my illness I was on the Dean’s List multiple times and in the Honors College. By the end of my college career, I had to drop out of my Honor’s Program and barely eked out a 3.0 GPA.

A case worker would have been very beneficial for my needs. Just getting through my day-to-day in university was exhausting. Keeping up with classes, handling the doctor’s appointments, and figuring out why my body was now failing me was an overload of stressors. Having a case manager in my corner to help with my challenging situations would have alleviated some of this stress. Having someone check in periodically to see if my needs are being met would have been a much-needed relief.

If the accommodations remain the same, I personally would not pursue a Master’s Degree in my field. My health would decline and I do not have trust in the system to bridge the gap between my needs and past expectations. I hope that in the future, anyone trying to achieve secondary education is not held back by their disability.

**HB1098.Chronic Conditions.DD Council.Support.pdf**

Uploaded by: Rachel London

Position: FAV



## Maryland Developmental Disabilities Council

CREATING CHANGE • IMPROVING LIVES

### House Appropriations Committee

March 8, 2022

#### HB 1098: 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 HB 1098.**

HB 1098 **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.<sup>i</sup>
- **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](mailto:RLondon@md-council.org)

---

<sup>i</sup> January 2012 *The Higher Education Opportunity Act: Impact on Students with Disabilities*. Madaus, Kowitt, and Laylor.

**HB1098\_PPC\_FAV.pdf**

Uploaded by: Santi Bhagat

Position: FAV

Testimony for Maryland HB 1098

Appropriations Committee

March 4, 2022



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

The Honorable Chairwoman Maggie McIntosh  
Appropriations Committee  
House Office Building  
6 Bladen St., Annapolis, MD 21401

March 4, 2022

RE: HB 1098/ SB 832

Dear Chairwoman McIntosh,

Thank you, Chairman McIntosh 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.<sup>1,2</sup> 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,

---

<sup>1</sup>Sarah 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/>

<sup>2</sup> 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.

diabetes, anxiety and other diseases. Our organization launched [Invisible Wave](#) to create a [community that is a safe space](#) and a platform for social change. The types 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 needs<sup>3</sup>, 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

---

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



ability to work are exactly what needs to be studied in Young Invisibles.

- 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.<sup>4</sup> 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.

---

<sup>4</sup> 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/>

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, 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.<sup>5</sup> 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.<sup>6</sup> 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

---

<sup>5</sup>National Collaborative on Workforce and Disability, "[Transition's Missing Link: Health Care Transition](#)", September 2012.

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

resources available in college. These students may have specific needs for education, dorm living, dining, career preparation, internships and campus

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 self-management. 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.<sup>7</sup>

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 Foundation<sup>8</sup> and the Higher Education Reauthorization Act in Congress<sup>9</sup>; 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.<sup>10</sup>

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.<sup>11</sup>

5. Foster Innovative Learning Models to Deal with Critical Issues Facing Young Invisibles: Innovative learning models are critical to this population because

---

<sup>7</sup>Royster, 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>

<sup>8</sup>Ibid

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

<sup>10</sup>Robertson, 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.

<sup>11</sup>Amelia Arria (center director) in discussion with the author, February 24, 2020.

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 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.<sup>12</sup>

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.<sup>13</sup>
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.<sup>14</sup>

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

---

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

<sup>13</sup>Doug 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>

<sup>14</sup>Maryland 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>

of young adults, thousands in the state of Maryland to be healthier and more productive.

**HB1098\_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 Chairwoman Maggie McIntosh  
Appropriations Committee  
House Office Building  
6 Bladen St., Annapolis, MD 21401

March 4, 2022

RE: HB 1098/ SB 832

Dear Chairwoman McIntosh,

I am Santi Bhagat, a physician and mother of a young adult who grew up with a chronic health condition. I founded [Physician-Parent Caregivers](#), 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 [Invisible Wave](#) 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 [first bill to study Yi](#) 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 [reintroduced this bill](#); 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 [report](#), 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 [Washington Post investigative report](#) 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 [Journal of Pediatrics](#) 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.

[Bill Gates has pointed out that the US has an extremely high dropout](#) - 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 21<sup>st</sup> 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 - HB1098.pdf**

Uploaded by: Stacey Benn

Position: FWA



*Office of the President*

**Morgan State University Testimony  
Dr. David Wilson, President**

**House Bill 1098** (*Delegate Pena-Melnyk*) / **Senate Bill 0832** (*Senator Feldman*)  
Public Institutions of Higher Education – Students With Chronic Health Conditions –  
Case Manager  
*Committee: Appropriations*  
**March 8, 2022**

**Favorable With Amendments**

Chair McIntosh, Vice Chair Chang, and members of the Appropriations Committee. We, at Morgan, thank you for the opportunity to share our position on House Bill 1098. 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 addition, 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 HB1098 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.

**HB1098\_USM.pdf**

Uploaded by: Joann Boughman

Position: UNF



**HOUSE APPROPRIATIONS COMMITTEE**

**House Bill 1098**

**Public Institutions of Higher Education – Students with Chronic Health Conditions –  
Case Manager**

**March 8, 2022**

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

Chair McIntosh, Vice Chair Chang and committee members, thank you for the opportunity to share our thoughts on House Bill 1098. 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.

House Bill 1098 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 nonmedical 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 House Bill 1098 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 continue 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 House Bill 1098.



### **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.