



*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 [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 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

