

## The Future of our Nation Depends on Young Adult Health

*“We call ourselves Young Invisibles because the world doesn’t see us or care about us - our conditions are often invisible. We also hide our conditions, for fear we’ll be misunderstood, ignored or judged.”*

An enormous health care challenge has now become an even greater crisis. An estimated 20 million young adults (18-34) have childhood-onset conditions<sup>1</sup> and many more acquire conditions in young adulthood. Now, with the ongoing abuse of opioids and other drugs, and Covid-related conditions that include widespread anxiety and depression, the number of young adults with chronic conditions has exploded. An emerging concern is whether Covid long haulers will join this group. Yet there is no system of care for these young people beyond pediatrics, nor do they get the support they need from educational institutions or in the workplace. There is no system for statistical reporting to identify their incidence, prevalence or health status, care and outcomes. They remain a largely invisible population and their future is at risk—with consequences for all of society.



1. [Prevalence 12-17 years](#)
2. [Prevalence 18 years and older](#)

Our nation must confront this critical domestic policy issue. [President Elect Biden](#) believes a president’s duty of care is for everyone and that all Americans should be treated with dignity and have a fair shot. To realize this, he must include the historically overlooked population of young adults with chronic conditions. These Young Americans need to know they are no longer invisible and that our nation’s leader cares about them and their health and civil rights. This vulnerable population needs to know they are valued and that they will get the support they need and deserve, so they too have a chance to share in the American Dream.

A Biden White House “Young Adult Health is Wealth” initiative is an example of what is necessary to prioritize this population and protect them and our nation. Unless we have a clear picture of the health of our young adults and a strategy to optimize their health, work and financial stability, our nation will suffer a loss in human capital, social well-being and economic status. We need a 21<sup>st</sup> century young adult chronic care model that integrates physical and mental health. The goals should maximize quality of life outcomes that include higher education, work, economic stability and societal inclusion.

<sup>1</sup> Prevalence of 19.96 million derived from rate of [26.2%](#) children with special health care needs and population of [76.2 million](#) 18-34 year olds

*“My pediatrician managed all my care and coordinated with my specialists, but since I turned 18, I only had one internist for 2 years who did the same. She helped me learn to understand my health and navigate the system – and she gave me her cell phone number. It’s so confusing and hard. I can’t find an internist who knows or cares about me as a young adult who’s trying to figure out how to manage my health and become independent and have a life.”*

*Natasha Bhagat, 33, Epilepsy, Maryland*

**BACKGROUND:** Just as we have seen tremendous progress in extending longevity for older people, medicine and technology now enable over [90% of adolescents who grew up with](#) previously fatal childhood conditions to survive into adulthood. One in four young adults has a childhood-onset condition, e.g., cystic fibrosis, congenital heart disease, epilepsy, migraines, Crohn’s disease, sickle cell anemia, Type 1 diabetes, ADD/ADHD, autism, cancer, HIV, genetic disorders and behavioral and mental health conditions. Every year, over [750,000 teenagers with chronic health conditions](#) enter young adulthood and struggle to transition to adult medicine.

Many continue to receive care in pediatric clinics and hospitals while others struggle to find young adult care in adult health systems that are designed for older people and the elderly. The health system is not designed to address the unique developmental and life stage needs of young adults. No longer can we presume that all young adults are healthy and that they can get by with sporadic visits for contraception, pregnancy, acute illnesses/incidents and accidents. Young adults need periodic physicals and mental health evaluations. We need to value their health, just as we do for younger and older people.

*“I work at the Children’s National Hospital cystic fibrosis center where we have young adult patients in their 20s and 30s, and even older ones in their 60s. Their pediatricians are scared to let them go.”*

*Cara Purdy, 24, Ehlers-Danlos Syndrome, Maryland*

Young adults with chronic conditions find themselves in the perfect storm:

- The health system is inadequately prepared to care for them beyond pediatrics.
- They do not have a home in federal or state government.
- Data are lacking on young adults with chronic health conditions.
- They are overlooked by public health, government and philanthropic entities.
- They lack adequate representation by advocacy groups and medical societies.
- Colleges and universities lack policies and supports for their health, academics and college life.
- The workplace lacks supports, programs and incentives to accommodate them.
- They have nowhere to turn except to their parents, which conflicts with their adult independence.
- Their conditions are often not apparent; they hide their conditions for fear of being misunderstood, ignored or judged. Society at large is oblivious to them.

The [National Academy of Medicine](#) states that young adults are distinct from older adults and need specific studies, policies and programs. The great need is that young adults with chronic conditions get the attention and services they deserve. The great benefit is that, by addressing the failures in our systems of care for this population, we will be serving *all young adults* whose health and health care has been neglected for too long. Investing in young adult health not only improves the present, it improves the future...of our nation.



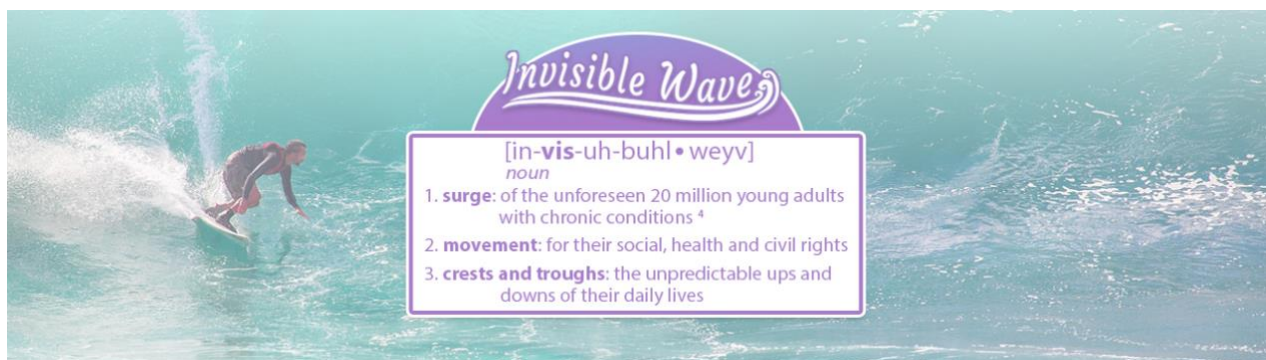
This crisis is not just about young adults, it's about their families. For those who have childhood conditions, the health and income of their parents often decline, the lives of their siblings are compromised—in a very real sense, their families are broken. For those who get married and have children, their spouses and children struggle to provide care and continue their own growth and development. These young families need a fighting chance to thrive.

RECOMMENDATIONS: [President Elect Biden made great promises](#) to [young Americans](#), the [LGBTQ+](#) and [disability communities](#) that include equality, affordable access to quality health care, support in [higher education](#) and full participation and representation for people with disabilities. Building on these promises, we need our new Administration to implement the following:

- Champion societal change by embracing young adults who live with chronic health conditions and advocating for their health and civil rights.
- Include a champion in the White House -- an expert advisor who can marshal the thinking and policies across and between agencies to solve the health, education, employment and housing issues for young adults with chronic conditions.
- Convene a White House multi-stakeholder summit on and with young adults with chronic conditions, the goal of which would be to develop a 21<sup>st</sup> century person-centered, virtual integrated young adult medical home embedded in a young adult chronic care model with a life-span approach.
- Create a demonstration program that develops patient-centered medical homes for young adults
- Include students with chronic conditions in President Elect Biden's higher education plans (e.g., [protect their health](#); [provide health care](#), academic accommodations and supports for chronic conditions, wraparound services, apprenticeships and work opportunities, and college life).
- Ensure the needs and rights of young people with chronic conditions are included in the efforts of the White House disability advisor (i.e., specifically include chronic condition accommodations).

*“My disability accommodations do not address the unpredictable nature of my chronic conditions. Due to strict attendance and exam policies that did not accommodate for my chronic conditions, I oftentimes had to force myself to go to class when I was physically unwell which worsened my health and academic performance; I had to sacrifice my health for attendance grades.”*  
Riya Chaudhry, 19, Fibromyalgia, PCOS, and Anxiety Disorder, University of Texas at Austin

[Physician-Parent Caregivers](#) is a voluntary non-profit dedicated to advancing quality health care and quality of life for young adults with chronic conditions through the [Invisible Wave](#) movement



Physician-Parent Caregivers

1901 Pennsylvania Avenue, NW, Washington, DC 20006 • 301.983.0406 • [physicianparent.org](http://physicianparent.org)