

Testimony for Maryland SB 147

Education, Health & Environmental Affairs Committee

January 20, 2021



*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

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.<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, diabetes, anxiety and other diseases. The types of diseases range from extremely common ones that most of us have heard of to the more rare conditions that only occur in a handful each year. But no matter what the illness, these young invisibles

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<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.

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. 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. Maryland's innovating

health information exchange (HIE), CRISP is making great progress in the area of information sharing, but little is being done to leverage the insights from CRISP to better understand how to identify gaps in care for patients with chronic illnesses, particularly those in the young adult population. We urge lawmakers in Maryland to consider the resources that have already been invested in CRISP and to consider how best to leverage existing infrastructure to better identify the health needs of teens and young adults with chronic illnesses.

3. Health care for most individuals, but especially teens and young adults with chronic illnesses is neither patient nor family-centered: The current health care system has not kept pace with the incredible development of technology; in fact, most of health care is still paid in a fee for service manner, particularly in the ambulatory settings in Maryland and surrounding states. The innovative progress made with global budgeting for hospitals has not necessarily spilled over into the outpatient settings, making care even harder for those who are trying to manage it on their own. Simple solutions such as telemedicine and integrated primary care (integration of behavioral health and medicine) are lacking and providers have little to no training in transitions of care.
4. 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 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.

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<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)

<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/>

## ***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, 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, taped lectures 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 and disabilities attending college

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

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. 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>7</sup> and the Higher Education Reauthorization Act in Congress<sup>8</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>9</sup> The Maryland Annual Collection Revision Report (MAC) is the core series of public data collections from Maryland postsecondary institutions. Data collected through the MAC allows MHEC to produce financial, research, and policy reports on critical higher education topics. While there was possible consideration for data collection for disabilities, there appears to be no

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

<sup>7</sup>Ibid

<sup>8</sup>Doug Sword, "Higher Education Bill Expected in Senate Soon", *Roll Call*, January 26, 2018.

<sup>9</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.

consideration for collection of data from students with chronic health conditions.<sup>10</sup>

We recommend a Maryland Task Force specifically designed to conduct a study on college student with chronic health conditions to ensure that these students will receive a reasonable, effective and appropriate education.

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>

2. Increased Awareness and Supportive Resources around Young Invisibles at Institutions of Higher Education: There is a critical need for societal awareness, and education. 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.

When well, it is important for students with chronic conditions to attend class and interact with the professors and other students. However, when

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<sup>10</sup>Maryland Higher Education Commission, "Maryland Annual Collection Revision Report", November 2012.

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

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>12</sup>

3. 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, taped 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>13</sup>

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<sup>12</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>13</sup>Theo Hayes, "Anne Arundel County Schools Bring Robots to Hospitalized Students", *WBAL TV*, October 24, 2017.

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>14</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>15</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 of young adults, thousands in the state of Maryland to be healthier and more productive.

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<sup>14</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>15</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>