

**Testimony of Anthony J. “Tony” Young
to the Subcommittee on Health of the
Committee on Energy and Commerce
hearing on
“The Implementation and
Sustainability of the New, Government-
Administered Community Living
Assistance Services and Supports
(CLASS) Program.” Thursday, March
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2322 Rayburn House Office Building

Good morning, Chairman Pitts, Ranking Member Pallone, and Members of the Health Subcommittee. Thank you for this opportunity to speak with you. My story shows the value of having a Community Living Assistance Services and Supports (CLASS) Program and how such a national voluntary program can help individuals and their families manage the impact when a sudden, unexpected event results in a life-long need for assistance with basic human functions.

Such an event can happen to anyone—at any time—and most individuals who need long-term services and supports have few feasible options for financing their care. Many typically rely on their own resources or on help from family members for the care they need. However, unless you are extremely wealthy with extensive savings, you will not be prepared for the financial and emotional costs to you and your family. That is why I am here today. My own experience demonstrates the need of the CLASS plan.

I am Tony Young, Senior Public Policy Strategist with NISH. NISH one of the two Central Nonprofit Agencies designated by the Committee for Purchase From People Who Are Blind or Severely Disabled, an independent federal agency, to help the Committee to administer the AbilityOne Program. The AbilityOne Program's mission is to provide employment opportunities for people who are blind or have severe disabilities in the manufacture and delivery of products and services to the federal government. AbilityOne helps thousands of people who are blind or have severe disabilities find employment. The program coordinates its activities with nonprofit organizations across the country to employ these individuals and provide goods and services to the federal government at a fair market price.

I work a fulltime job and volunteer in my community. I am married to a fulltime working spouse. We have one six year old child. We pay taxes, a home mortgage, and utilities, save money to send our son to college, and put away some money to live on if we have a chance to retire. At first glance, our life appears to be the same as millions of other taxpaying Americans. As you will read later in my testimony, a deeper look tells a much different story.

The CLASS Plan Offers a Pathway for All to Contribute and Plan for Their Future

There are three things I would like you to keep in mind during my testimony today.

I am one of the fortunate few, perhaps even rare example. I was not forced to live in a nursing home nor become impoverished in order to be eligible for Medicaid obtain the vital long-term supports and services I need. What makes my circumstance different than thousands of other individuals with significant disabilities? I am one of the .05% (1/2 of one percent) of individuals with a significant disability who received SSDI/SSI who now are able to be gainfully employed and no longer need dependent upon public income, Medicaid, or Medicare programs. Now I am a productive taxpayer, and I am not adding to the cost of Federal and state expenditures.

The CLASS program is a huge step forward for the nation. It offers a solution to for all of us to help finance the challenges that lie ahead in preparing for an unexpected event. I wish the CLASS program had been available to me as an 18 year-old student and to my family prior to my accident. Had someone like me had CLASS coverage prior to such an unexpected and life-changing accident, my family and I would have had some security that the personal assistance and long-term supports I needed would be available to me. I want the opportunity for my wife—and eventually my son—to plan for a future disability.

Keep in mind that when a person is born with a disability, acquires one in young adult through an accident, or develops disabilities in their later life, that the person does not automatically trigger CLASS benefits. In order trigger benefits, an individual must meet a threshold of functional limitations. There are different thresholds and different benefit levels depending upon the level of limitations. Some individuals will choose not to trigger their benefits at that time. Also, importantly, individuals must continue to pay premiums while receiving benefits.

I know that some of you have concerns over the solvency of the program. Believe me, I want and need CLASS to be solvent, too. I want for my family and for millions of other Americans to have a sustainable program for their future. As we have heard today, the HHS Secretary has the authority—indeed, the responsibility—to ensure that the program is solvent for 75 years. Secretary Sebelius has announced important steps to ensure the sustainability of the CLASS program by addressing earnings minimum levels, adjusting premium levels to account for inflation, and strengthening fraud, abuse, and waste loopholes that might threaten the program. These reforms are important to the program and I believe that the Secretary must be given the time to make these and other changes to strengthen the CLASS program.

- CLASS is a national program to help insure coverage for future disability.
- It is financed through private contributions. No taxpayer dollars are involved in the contributions or benefits of CLASS. That is important to all of us. That we finally have a program that is not publically financed and that is accessible to all working individuals to take personal responsibility to plan for and provide those vital long-term services when life throws us an unexpected curve.
- Students, young people, and young adults now know disability is a natural part of life—kids see it in schools, parents know child either at birth or laterworking adults know the cost of taking on financial and emotional costs of caretaking without financial resources.
- There would be no “medical underwriting” feature to the program; different from long-term care insurance. This is important so that individuals can not be excluded based on pre-existing health issues or disabilities.

- Cash benefits are available with no life-time caps, unlike benefits from long-term care insurance. The flexibility of cash benefit to use as is needed to purchase just the help that is needed is invaluable
- I believe that the CLASS program will provide new opportunities for jobs—paid assistance in the private sector or paid home modifications.
- I think the ease of enrollment—voluntary employer enrollment or alternate options—and the efforts that HHS is making directly with employers to develop a simple, trouble-free process will be very inviting to individuals of all ages and employers

Background

I require substantial personal services to maintain my daily work and family activities. Every morning an assistant helps me shower, shave, toilet, eat breakfast, dress, and prepare for work. Two evenings a week and on weekend mornings an assistant helps me with bowel and bladder care. This minimal platform of 18 hours per week of paid supports costs more than \$17,000 annually. This money, including the amounts withheld for Federal and State income taxes, FICA taxes, unemployment insurance, and other fees comes from our family budget.

That is not the only expense the family incurs to support me. That initial \$17,000 helps with the Activities of Daily Living—the ADLs. Many other functions need support assistance. A family of three must go food shopping; do laundry; clean house; take out trash; recycle paper, glass, plastic; pay bills; and other routine activities. There is also the evening assistance I need five evenings when we cut down our expenses by not paying for assistance. My six year old helps by doing his chores, but nearly all of these activities must be done by my wife. Even though it can have a financial, physical, and emotional struggle, the process works much of the time.

Life has not always worked this smoothly. I was 18 when I sustained my disability while body surfing. In high school I was very active in sports, lettering in football and track; I was selected as Second Team All-Met Right Guard in 1969. There were social clubs, school activities, summer jobs, dating, dances, pool parties, and preparing for college. It all ended abruptly and without warning on a hot summer day in August. I went from near total independence to near total dependence in the crunch of a C-4 vertebra.

After ten months of medical and physical rehabilitation I was sent home to live with my parents. There was no information available on how or where to get help. There were long months when my parents managed all of my personal care needs while working fulltime. We were fortunate to have good employer health insurance at that time; so medical bills did not bankrupt the family. This continued for nearly three years.

Slowly we discovered that some services were available. They came from a local visiting nurse service. I received home visits for personal care, physical and occupational therapy, and medical monitoring. These services helped to relieve some of the personal care needs of my parents, but it soon became apparent that I needed more flexible and responsive supports.

I wanted to work. I had always worked since I was old enough to responsibly use a lawn mower and other tools. At age 23, I was immobile from the shoulders down with no skills beyond a high school diploma, a senior lifesaver certificate, and a pool manager's license. This skill set was not in high demand by employers at that time, or any time. It was absolutely necessary that I obtain a college degree if I was to work. Fortunately, my Virginia Department of Rehabilitation Services counselor agreed.

When I began scheduling college courses, I encountered problems between the home health system and the higher education system. College courses begin early. Laboratory and library time meets on variable timeframes. This is before the Internet; no online study. Note takers and typists had to be scheduled; papers had to be prepared on a typewriter. The nurses, aides, and therapists all had their own schedules. Generally, these times were not complimentary.

Closing

I am testifying today not on my own behalf but for individuals who are likely to develop disabilities in the future. My experience leads me to strongly believe that the CLASS program is a long awaited opportunity for all Americans to share in the responsibility for preparing for their future long-term services and supports. Unlike forty years ago when my accident occurred, I want Americans to know they have a way to gain some financial and emotional security for an unknown future. Believe me; life is full of unexpected turns.

I urge Congress to allow the Secretary to move forward in her efforts to implement and strengthen the CLASS program. We need it now. I am available to answer any questions you may have.