

“I am no bird; and no net ensnares me; I am a free human being with an independent will.”

- Charlotte Bronte

The term independence can take on many different meanings depending on where you are and what's most important to you. It encompasses a person's right to autonomy; the ability to make personal decisions without the forceful opinion of others. Individuals with disabilities – especially those who require consistent assistance completing activities of daily living – find it challenging to live independently. One main reason is a need for a network of paid caregivers who can provide assistance with daily needs. Acquiring this level of care in the home setting has been a battle in the US for many years. In 2015, there was a shift in how Florida provides long term care to individuals who chose to live at home rather than in an institutional setting. This shift created a partnership between Medicaid and private long term care insurance providers. While still bumpy, the partnership has provided opportunities for disabled adults to acquire much needed care at home rather than being forced into a nursing home. While every person's definition of independent living differs, when it comes to long term care assistance there are two barriers people with disabilities face: access to insurance coverage to pay for services at home and informed choice.

Staying at Home is Key

One person may define independent living as having his or her own place to live. Others may define it as simply managing their own paid caretakers who provide the majority of required assistance, while still living at home with mom and dad. Regardless of the definition, every person has the right to live in his or her own home rather than be forced into a nursing facility. In my life, I define independent living simply as living *my life my way*. I knew at a young age that I wanted to move out of my parent's home and get my own place. My goal was not to always depend on my mother to provide me care, but instead to live independently by finding a way to acquire long-term care coverage that would pay for personal care assistants to help me on a daily basis. Due to my disability, getting dressed, using the restroom, cleaning my home, driving, etc. are all things that I cannot do on my own. However, living in an institutional setting was never an option. Thankfully, the federal government agrees with me. In 1999, the Supreme Court decision in what's known as the *Olmstead* case clarified that it was discriminatory to unnecessarily institutionalize individuals with disabilities. The Court held that states must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated¹. While in theory this provision of the ADA is great, in reality states struggle to allocate appropriate funding for home and community based services (HCBS). Many states have long waiting lists that are opened only when a person currently in the program either moves out of state or passes away. In late 2013 Florida began to synchronize their HCBS program with private insurance companies, creating a managed care system overseen by Medicaid. By 2015, all counties in Florida now offer home-based services for eligible individuals with disabilities, with a very short (typically 30 days) waiting period.

¹ ADA.GOV

Informed Choice – My Way or The Highway

Once you are finally in the HCBS program, you are given two choices: To have your care provided through a home health agency or through patient directed care options. The latter is the best option for me, but there are many people who prefer to use the services of a nursing agency. Patient Directed Options (PDO) is a system where recipients recruit, hire and manage their own caregivers. They are responsible for filling out timesheets, monitoring their employees and managing all human resources tasks with no supervision. While it may sound somewhat daunting, living my personal definition of an independent life is great fun. It's like running a business that has NO option of failure. Today, I hire personal care assistants who come to my home 365 days per year, 7 days a week. While sometimes a bit of a juggling act, managing my own network of caregivers makes life that much sweeter, because by learning how direct my care, I'm able to truly live *my life, my way*.

For more information on Florida's Home and Community Based Services, check out the following links:

- ❖ Agency for Health Care Administration Long Term Care Snapshot:
https://ahca.myflorida.com/Medicaid/statewide_mc/pdf/LTC/SMMC_LTC_Snapshot.pdf
- ❖ Olmstead: Community Integration for Everyone:
http://www.ada.gov/olmstead/olmstead_about.htm
- ❖ Statewide Medicaid Managed Care (SMMC) - Long-term Care Program:
<http://www.flmedicaidmanagedcare.com/GeneralInfo.aspx>

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