

Disability Integration Act – Untying the Institutional Bias

By: Lorinda Y. Gonzalez

For to be free is not merely to cast off one's chains, but to live in a way that respects and enhances the freedom of others. - Nelson Mandela

2016 is an exciting year for disability rights. It's the first time in a long time that major federal legislation is on the horizon to positively support the independent lifestyle of individuals with disabilities who require long-term care assistance. While different for each person, long-term care refers to the need of continual and regular assistance with personal needs. Help getting dressed, using the restroom, brushing one's hair & teeth, showering, meal prep and getting ready for the day, all encompass long-term care needs that are common. Many people with various disabilities – including myself – are willing and eager to participate in their communities but need help with their activities of daily living every single day. The key to integration in many situations is to ensure we get the services we need without restriction.

Is Getting Help All that Hard?

In November of last year, Christin Bates of Dallas Texas had to go to court to fight for her right to receive home health care assistance. This brilliant young woman is a PhD student at Dallas Theological Seminary. Diagnosed with spinal muscular atrophy at the age of three, she requires assistance throughout the day. “I need help with everything from transferring from my bed to my wheelchair. I need help going to the restroom. I need help getting dressed,” she says. “My physical limitations are pretty severe¹.” Texas State only provided her 5 hours of assistance per day – nowhere near what she actually needed. After numerous letters and phone calls to the state, she was offered another option – to be placed in a nursing home.

Health insurance companies and state Medicaid programs are notorious for making it next to impossible to acquire home care services on a long-term basis. Instead of providing services based on medical need, payers have integrated a number of policies to decrease and limit services, which

¹ The Dallas Observer: <http://www.dallasobserver.com/news/exclusive-dystrophy-wrests-state-christin-bates-from-theology-aid-but-texas-medicaid-wont-7192170>

in turn reduces their expenditures. In the past, if a person required help with three or more of these activities of daily living, the go-to option for most states was to force them into an institutional setting rather than proactively paving a way for them to stay home. *Why?* Because the federal government pays more for institutional care than it does for home care.

“Across the board, everyone agrees that the institutional bias is the number one thing holding people with disabilities from being full participants in society. The institutional bias lies in the fact that nursing homes are, undeniably, favored by the federal government, in that they receive more federal dollars than any other form of long-term care. Meanwhile, community based services, which is long-term care that you can receive in the comfort of your own home, is getting the short-end of the stick. This results in too many people with disabilities living in nursing homes, rather than in the community, simply because that’s where long-term care will be paid for. - Leah Smith, Center for Disability Rights.

Change is on the Horizon

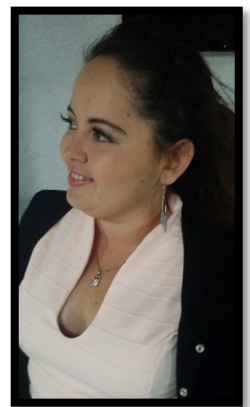
While an institutional bias is an archaic concept, thankfully the public is beginning to acknowledge that forcing a person into a nursing home setting solely based on their need for regular daily assistance is not only discriminatory but also a violation of their civil rights. At the end of 2015, a piece of legislation came into play, seeking to change this practice and give individuals with disabilities a right to choose how and where they live. Sponsored by Senator Schumer of New York originally, the Disability Integration Act (DIA) supports eliminating the institutional bias by addressing the need for Long Term Services and Supports (LTSS) in their homes. If passed, the new law will be structured similar to the ADA and require that all 50 states throughout the US, and insurance providers that pay for LTSS, change their policies to provide community based services first and offer HCBS to individuals currently residing in institutions. DIA federal law will support the rights of all individuals with disabilities to live in the freedom that America is founded on.

While home and community based services are currently available in most states, there are typically long waiting lists. In Florida, the waiting list was at one point as long as ten years for services. DIA would make it illegal for states and insurance companies to deny services for home and

community based services by integrating waiting lists, rigid screening processes, putting a cap on services, paying home health workers meager pay, etc. Personally, I've battled with my own insurance providers over the years because of some of these exact issues. It wasn't until recently that my health care provider began paying my personal care assistants a reasonable hourly rate. Attempting to hire and keep personal on staff when they are paid less than minimum wage creates a dangerous and unfair situation for individuals with disabilities who depend on these services for their livelihood.

According to the proposed legislation, "No public entity or LTSS insurance provider shall deny an individual with an LTSS disability who is eligible for institutional placement, or otherwise discriminate against that individual in the provision of, community-based long-term services and supports that enable the individual to live in the community and lead an independent life²." If passed, DIA will make it illegal for states and insurance companies to deny persons with disabilities access to care services provided in the home setting. However, the act still has a long way to go. To keep tabs on this important piece of legislation, check out ADAPT's website for current updates – www.adapt.org - as well as www.congress.gov for up to date information on how the bill is progressing.

Author: Lorinda Gonzalez resides in South Florida with her family and service dog, Remy. She was diagnosed with Spinal Muscular Atrophy at the age of three, and has used a motorized wheelchair for mobility since the age of nine. As an avid writer and reader, she has worked as a grant writer and editor since 2009. With the help of her family, it has grown to become a successful endeavor. Lorinda holds a Bachelor in the Arts Degree in English Writing and Rhetoric, and is currently completing a Masters of Arts Degree in Communications. She is a co-founder of NMD United, a 501c3 and on the board of multiple non-profit organizations. In her free time, Lorinda enjoys spending time with family and friends, painting, listening to music, and traveling to historical locations.



² <http://www.adapt.org/legis>