

Pedro's Story

It's been a long journey since my spinal cord injury happened. At the time, I was living in Puerto Rico, but due to my medical problems, a nurse recommended that I come to the U.S. and live with my extended family. I was in bad condition, and shortly after I arrived in the U.S., I ended up in the emergency room with multiple problems, including constipation, incontinence, a urinary tract infection (UTI), skin ulcers, and respiratory problems.

When I was admitted to the emergency room, I weighed only 113 pounds and felt very weak. I was admitted to the hospital, and the doctors were able to stabilize my condition and helped me to put on weight. I was eventually discharged to a long-term care facility where I was assigned a Spanish-speaking primary care nurse practitioner, something I had expressed was important to me.

What is Important to Pedro:

- Working with a Spanish-speaking health care provider
- Living at home, not in an institution
- Increased independence
- Socializing with friends and family and feeling 'normal'

I was in and out of the emergency room several times with pneumonia and UTIs. I did not want to live in an institution forever. I wanted to be able to live a normal, independent life again at home. Eventually I was transferred to an inpatient rehab facility where they helped me to prepare for transition back home and into the community.

Participant-Centered Primary Care

I was assigned a care coordinator who coordinated my care with the rest of my care team and worked with me to understand my needs and priorities. My primary care nurse practitioner helped me manage my medical conditions and to become healthier so I didn't have so many bladder problems and skin ulcers. Due to all my recent life changes, my primary care nurse practitioner thought it would be a good idea for me to be assessed for behavioral health issues. While she wanted me to see a counselor, she was supportive when I explained that I would be more interested in peer support (e.g., attending support groups, peer counseling, or education programs).

My care team, led by my primary care nurse practitioner and care coordinator, also supported me in other ways. I learned when and how to contact them to help prevent unnecessary ER visits. I also had a mobility assessment conducted so I could get a wheelchair with the seating and positioning supports that I needed, and started getting Botox injections to help with my muscle spasms.

The Impact of Participant-Centered Primary Care on Pedro's Life

I now live in accessible, subsidized housing with my mom, and I have personal care attendants who assist with my care. My primary care nurse practitioner and other members of my care team sometimes conduct home visits to help manage my medical needs. I am more independent now that I use a powered wheelchair, and I attend a weekly peer support group where I have made several friends. I also participate in community classes where I am learning English as a second language.

Currently, I do still have some skin ulcers, but I am at a healthier weight now and I'm feeling stronger. The Botox has helped to manage my muscle spasms so I am able to wear sneakers again. I will even be evaluated soon for a driving assessment!

Disclaimer: Names and identifying details have been changed to protect the privacy of individuals.

You can find additional resources regarding the Disability-Competent Care Model [here](#).