

Stories from Home

SELF-DIRECTION DURING THE COVID PANDEMIC



Kevin was looking to hire a replacement worker just as the COVID-19 pandemic hit New York. He is a participant in New York's Consumer Directed Personal Assistance (CDPA) program and requires 24/7 support as someone with C5/C6 quadraplegia.

“Regardless of the pandemic, I like the ability to choose who I want to work with, check references, and control who I bring into the house.”

Kevin usually employs six workers at a time. His night staff administer medications, dress him, transfer him to bed, change his catheter bag, and intermittently turn him to prevent pressure ulcers.

There has been a well-documented shortage of direct care workers for years, but Kevin learned that the pandemic has exacerbated this issue exponentially. In his search for a new night worker, Kevin reached out to approximately eighty professional caregivers, but received zero responses. “People were making enough

money on unemployment, so they were less incentivized to come to work. Other people, under the circumstances, didn't want to come into someone else's home. It was pretty hard.”

Fortunately for Kevin, CDPA, a self-direction program, allows participants to hire some family members. He was able to hire his adult son, who had flexibility in his schedule due to the pandemic, when finding workers outside his family proved impossible.

“I don't know what I would have done if my son wasn't around. It's kind of scary.”

During the pandemic, receiving care from family or others who are sheltering in place together greatly reduces risk for those most vulnerable. “I am compromised in my ability to breathe, I don't have any muscles in my diaphragm, so the virus would be deadly for me,” said Kevin.

When asked what he would do without self-direction, Kevin replied, “I'm at a loss for words. I'm really not sure.” For Kevin and numerous others, self-direction has been a lifeline during the pandemic.