

STORIES FROM HOME

Self-Direction during the COVID-19 pandemic



RYAN is a 35-year-old who has lived in New Hampshire for all his life. He was born with a birth defect called Osteogenesis imperfecta, also known as Brittle Bones Disease.

Ryan lives an independent life, driving a modified vehicle and working at Granite State Independent Living, a nonprofit that promotes quality of life with independence for people with disabilities. He is an advocacy coordinator, tracking legislation in the state and informing individuals with disabilities on how it might affect them. Often when a bill is introduced that impacts individuals with disabilities, Ryan will testify in front of senators and representatives to advocate for disability rights.

"I am not able to walk, and I use a power wheelchair to get about. My bones break and fracture very easily, so I have to be careful about any sort of physical activity that I do."



Ryan has received personal care services for over 15 years, through two self-directed programs: the Personal Care Attendant (PCA) Program and the Personal Care Service Provider (PCSP) Program. While he self-directs his services and supports through both programs, there are different rules and eligibility requirements that impact who Ryan can hire.

Ryan was able to hire his father through the PCSP program, but the PCA program typically does not allow family members to be hired as paid caregivers. Instead, Ryan hired a friend to provide additional care through the PCA program. Ryan's father has a full-time job in addition to working for Ryan and provides support during his days off.

"It was difficult juggling what I was able to receive care for."

Prior to utilizing self-direction, Ryan received services from an agency that would send workers to his home. This meant that, throughout one week, there were often three or four different people coming in to help him. Ryan remembered how frustrating it was to work around last-minute schedule changes. He noted how challenging this made attending legislative sessions that were often scheduled without advance notice, "I really like handling my work schedule." Because of his dedicated and trusted staff he employs in self-direction, Ryan's service needs are met and he can still maintain the flexibility required to meet the demands of his job.

During the COVID-19 pandemic, New Hampshire temporarily allowed family members to be hired in the PCA Program through emergency legislation. However, Ryan was reluctant to make staffing changes because it was unclear how long this change would last. If he were to hire his father in both programs, then his father would have to quit his full-time job. This could cause significant problems when the emergency legislation ends. Additionally, Ryan noted the low pay-rate and lack of benefits as further reasons his father cannot be his full-time caregiver, "Medicaid reimbursement rates are low and had been low for a very long time."

"Without the kind of personal care that I receive at home, I would have to be in some sort of living facility because I'm not able to take care of myself. But that is just not the kind of situation I would want to end up in. I like my home, I like my community, and I want the level of independence that I have. I want to maintain that for as long as I can."



Ryan is in a unique position to understand the many complexities of home and community-based services. He has experienced how different program rules and regulations can impact how he receives services. After trying multiple models, Ryan enjoys being able to self-direct, particularly having the ability to hire family and friends.