



Stories from Home

Self-direction during the COVID pandemic

Marissa is a 32-year old woman with Down Syndrome. She lives in her Utah home with her adult siblings, who have a variety of disabilities, and her mother. Marissa is in a self-direction program but, prior to COVID-19, was unable to hire her mother as a paid worker.

Marissa needs her mother, Kim, to help her with a variety of tasks including personal hygiene, laundry, portion control when eating, shopping for personal needs, doctor appointments, and other frequent and consistent monitoring to ensure her safety.



Prior to COVID-19, Marissa participated in a variety of activities, including day habilitation and a job at the recycling center at Utah State University.



When the pandemic began, Kim immediately pulled Marissa out of all day activities. Marissa is considered high-risk for COVID-19 with two heart defects and respiratory problems. To



ensure her safety, Marissa's cardiologist recommended to continue to keep her at home.

It has been difficult for Kim to maintain full-time employment as Marissa requires so much support. Kim has worked part-time jobs so she has better availability to care for her daughter.

“One year we attended over 89 doctor and disability appointments. And people would ask me, 'When are you going to get a job?' That has been frustrating as if what I was doing for my daughter wasn't work.”

It's important to note that when Kim misses work to take care of Marissa's needs, she does not get paid.

During the pandemic, Kim learned she could receive payment for caring for Marissa. Marissa's support coordinator was able to reallocate funds from services Marissa wasn't using during the pandemic, such as the day program and transportation, to pay Kim as Marissa's direct care worker.



“It was huge and very validating to finally have the caregiving I do recognized as actually doing work. The income was so helpful since I had lost my three part-time jobs due to COVID. I felt like I had a safety net and hoped that it would become a permanent option, like several other states already allow.”



Kim has been impressed with how well her family has fared during the pandemic.

“It was stressful long before the pandemic trying to juggle the safety and needs of my daughter, but with the parent payment option during COVID, life felt calmer and more focused on the challenging needful things.”

As some pandemic restrictions are being lifted, Kim hopes that the long-term realities of parenting a child with disabilities aren't disregarded by those who make funding decisions. Family members know their loved one's needs best and should be paid accordingly for their care.

