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Student seeks community in digital spaces

Began research due to son's rare disease, isolation that came with it

WVU Today

The coronavirus has driven us indoors and separated us from coworkers, friends and loved ones. That's nothing really new for Sara Loftus, a West Virginia University geography doctoral student who is studying how to build an online community.

"Since I have worked from home for more than 20 years, COVID-19 hasn't changed my day-to-day very much," Loftus said in a remote interview from Huntington, where she cares for her adult son, who lives with life-threatening and technology-dependent medical conditions. "What it has done is allow a window into my world for those people around me."

In caring for her son, which also involved weekly trips to Columbus for most of his childhood, Loftus found herself socially and geographically isolated. That experience motivated her to pursue a career in and study digital caregiving.

"My son's medical and developmental needs prevented us from participating in many typical childhood activities. The internet became a place where I found opportunities for work, socializing and much-needed resources and information about my son's rare disease," Loftus said. "For me, these digital spaces became more real than the physical spaces in the community."

Today, she is investigating how other caretakers use digital spaces for all types of care, including health care, self-care and parenting.

"I am working to under-

stand ideas about co-presence, or how these digital spaces allow us to be in more than one place at a time. I'm also interested in understanding how care is expressed in digital communities, such as self-care and caring for others," Loftus said. "Fundamentally, my research is about understanding how communities form and sustain themselves, especially over places multiple times."

Her research directly supports the nonprofit organization she founded in 2016, the Center for Supported Learning.

"My research is about understanding how caretakers use the internet to help them take care of themselves and the person they are caretaking for in their everyday lives," Loftus said. "I want to know more about the relationships they build with other people online, what online places they visit, how they interact with those digital places and what their digital daily lives look like. I then try to make sense of the impact of this digital dimension on the rest of their lives."

The organization works with neurodiverse youth and young adults with Autism Spectrum Disorder and other developmental disabilities.

"At the core of what I do is a concern with community and creating spaces that support people who are marginalized by society," said Loftus, who is the executive director of the organization. "We do this by building collaborations with community organizations, institutions and other allies interested and willing to provide inclusive lifelong learning opportunities like urban gardening, fine arts, digital technologies, dance, theater, music and photography."

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