

Health Care Accessibility Beyond Social Services: Considerations for Aging Out

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Introduction: A testing conundrum

On March 6, 2020, eight months into my dissertation fieldwork on aging out of Kentucky's child welfare system, Kentucky confirmed its first COVID-19 case. The commonwealth immediately went into lockdown (Beshear 2020). My participant observations with advocacy organizations and service providers became Zoom calls; my one-on-one meetings with former foster youth became text messages and phone conversations. I initially met Allison¹, a former foster youth, several years ago when I worked in a residential care facility in Kentucky. She has since "aged out," or left state custody, without a definite destination. When I started fieldwork in August 2019, a local service provider put us back in touch. As the lockdown began, we had been meeting regularly for meals and talks for about seven months.

During the first few weeks of lockdown, Allison and I continued our conversations via text, swapping news stories, and fact-checking each other's sources. As essential workers, Allison and her boyfriend continued working their regular schedules, hoping they wouldn't bring the virus back to the rental they shared with two friends. Allison avoided her grandmother and friends with young children when not at work, afraid she was a carrier. She was alarmed after reading reports of steep casualties in Italy (Mounk 2020), and worried about the possibility of the virus overloading Louisville's health infrastructure. After a tense conversation about her sore throat one morning, she asked me how to get tested.

At the time, Louisville's testing capacity was limited; because she was nineteen and relatively healthy, Allison was unlikely to be prioritized for testing. She'd have to call the health department, who would ask her about symptoms and exposures to anyone who had tested positive, then schedule an appointment. I gave her the health department's number and described their screening procedures, explaining that she'd likely be told to isolate for two weeks and go to a hospital if things got worse.

Leveraging clinical ambiguity in a pandemic

"What do I tell them then? Can I just get a bed at the hospital in case?" she asked me and began proposing ways to preemptively ensure a spot. Her first idea was to tell clinicians she lost her sense of taste, reasoning there was no test for taste loss. Next, she suggested imitating a fever by wearing sweatpants and running in place before nurses took her temperature. However, her primary concern was her boyfriend. "He has a heart condition, since birth – would they treat him if they knew that?" she asked.

¹ A pseudonym.

I reminded Allison that if she needed hospitalization, a performance of symptoms would probably be unnecessary. The bigger concern, she pointed out, was her insurance. A retail worker who eventually lost her job during the pandemic, Allison was uninsured when Kentucky's lockdown began. I asked if she knew that she qualified for Medicaid coverage as a former foster youth (Children's Bureau 2015): she said she had no idea, and asked how to enroll.

The questions Allison asked me centered on how to protect herself and loved ones in uncertain times. She managed the uncertainties of her carrier status and the lack of testing by avoiding friends and family. By emulating unverifiable symptoms and strategically withholding information about pre-existing conditions, Allison could introduce new clinical uncertainties that would ensure care for herself and her boyfriend. I read Allison's problem-solving strategies as a kind of specialized knowledge about leveraging clinical ambiguity acquired through years of out-of-home care: like many former foster youth, she learned "what it takes to *survive inside*" care settings (Greer 2020, 42). This was knowledge that translated well to managing biological uncertainties in a pandemic.

Young people navigating bureaucracy

However, as Mulligan and Castañeda (2017) illustrate in their analysis of the implementation of the Affordable Care Act, getting *insurance* is markedly different from getting *care*. Mobilizing health care bureaucracy requires specialized knowledge of documentation and regulations – expertise learned through training and experience (Carr 2010a) – alongside patience, flexibility, and carefully calibrated self-presentation (Boyer 2008). Effective performances of "deservingness" are particularly fraught for young people, who, as Silver (2010) demonstrates in her work on American Independent Living Programs, are often dismissed for their race, age, and gender. Bureaucracy scholars have also analyzed bureaucracy's effects and failures in Cyprus, Greece, France, Britain, and India (Navaro-Yashin 2007; Cabot 2012; Kafka 2012), highlighting how bureaucratic opacity and sluggishness (Mathur 2014) frustrate, annoy, or frighten people who depend on services.

When Allison tried to enroll, she encountered dismissiveness and non-responsiveness from social services. Although she understood how to navigate clinical settings, she lacked vital information about accessing their parallel service bureaucracies and was understandably frustrated about her interactions with bureaucrats when she asked for help. After multiple attempts on her own, she asked me to send an email on her behalf and received an insurance card within weeks.

Conclusion: Anthropologists as researcher-advocates

Although I'm not a caseworker, bureaucrats and young people often interpellated me as one. Service providers asked me to help young people navigate bureaucracies, while young people asked me to leverage my relationships with service providers when no one answered the phone. I was sometimes hesitant to refer young people to social services, concerned with inadvertently exposing them to unwanted surveillance (Carr 2010b; Fong 2020). However, with Allison's request, I realized the importance of becoming what Silver calls a "researcher-advocate," mobilizing "situated bureaucratic knowledge" to "help with whatever participants needed" (Silver 2015, 14). During the pandemic, Allison needed insurance, and positioned me as someone who could help.

Participant observation is a powerful method for anthropologists because it demands that we attend to material needs, local knowledge, and relationships simultaneously. I argue that the pandemic changed the boundaries of “whatever participants needed” beyond the strictly bureaucratic guidance, particularly for young people with limited support networks. My role as a researcher-advocate certainly included modeling effective bureaucratic engagement and leveraging my field relationships on Allison’s behalf. However, it also included becoming a sounding board for creative problem-solving, an information source, and someone to text when she was worried about her loved ones. As health care becomes increasingly bureaucratized and opaque, it’s essential that anthropologists adopt researcher-advocate roles, attending to what young people need in and outside of bureaucratic spaces.

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