



Real life stories when one has a disability in the time of COVID-19

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Abstract: With the COVID-19 pandemic, many challenges and problems have occurred across all populations; however, for individuals with disabilities, the challenges are often significantly exacerbated by the additional problems of access and inequity. This article describes five real life stories of individuals with disabilities who have been seriously impacted by the pandemic. We have described the individuals' disabilities, the complexity of the situations amplified by the pandemic, and how it has jeopardized the health of these individuals. As these individuals navigated this new uncharted territory of COVID-19, they often were left with few resources and an inability to access their traditional resource networks. We have documented each story and integrated relevant sources that support the jeopardy of the individual involved. We hope that this article may assist readers in understanding the perils of progressing through COVID-19 with a disability.

Keywords: Anxiety; attention deficit disorder; autism spectrum disorder; COVID-19; developmental disability; dyslexia; intellectual disability; intersectionality; learning disability.

The only marginalized group in the United States for which legal segregation is still allowed is the group containing those of us who have a disability.[1] We allow segregated classes for some students with disabilities. We even allow segregated schools for certain students with disabilities. This falls under the Individuals with Disabilities Education Act (IDEA) and the continuum of services.[2] One of the authors worked for three years in a private, profit-making school for students with emotional and behavioral disorders.[3] The company owning this school also ran prisons. The similarity between prisons and schools is sad. The needs of people with disabilities is not the priority; the bottom line is.

Added to this, for many students with disabilities, is a layer of institutionalized racism. Disproportionality has been well documented, with black and brown students being over identified as having emotional and behavioral disorders.[4,5] This may be further compounded if the student's first language is not English and if their family's immigration status can be questioned at will. Language and cultural barriers cause further discrimination as does the fear of deportation. [6] Add another layer: laws and policies affecting education which are based neither on research nor on logic. Add one more layer: the effects of the COVID-19 pandemic which compounds the inequity in digital access for those with lower socio-economic status.

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The following are five stories where the intersectionality, as well as the failures of our society, become apparent. We have outlined these personal stories that we have encountered in our work to portray the injustices that the COVID-19 pandemic has made strikingly more visible for students with disabilities and for their families. We hope through sharing these stories that all of us may reach a greater understanding of the challenges and inequities that arise on a regular basis for many people in our world.

Story #1

A college student who is attending a Midwestern university has significant specific learning disabilities and attention deficit disorder (ADD) with hyperactivity. As COVID-19 entered the picture, the student needed to return to their Chicago home. Shortly after their return, their aunt died of COVID-19. The student and their family needed to travel over one thousand miles to support the surviving family through this crisis. They did not have access to internet during these travels (again demonstrating the inequity in digital access for many), so the student fell behind in course work.

The professor worked with the student and assured them that they could catch up. Upon return to Chicago, the student was living with another aunt who became angry and locked them out of the house. They didn't have access to their laptop, textbooks, and other tools necessary to do class work (e.g. paper for notes), and the student was homeless for about two weeks in the midst of the pandemic. When they finally gained access to a computer, text, and other necessary materials, they were physically not feeling well, and unable to re-organize and complete assignments for the semester. The student failed the course which was a requirement for graduation. They had planned to graduate this past May.

This student had taken on leadership positions on the college campus and was on target for graduation, but due to COVID-19, their life plans have had a significant change. First jeopardy: poverty and unstable home situation. Second jeopardy: COVID-19 causing the death of a significant family

member and other family members are without health care. Third jeopardy: specific learning disabilities and ADD with hyperactivity resulting in a chaotic, disorganized response and therefore unable to complete their college degree. This story demonstrates the intersection of vulnerabilities for this student.

An article written on the webpage of the American Psychological Association speaks to the reality that due to distinct challenges which individuals who have disabilities face during the pandemic, these students may experience worsened mental health.[7] Additionally, it is then harder to access essential mental health services, supplies and information. This student was faced with a higher degree of social isolation due to being homeless and cut off from their primary family - home and family are essential resources for most of us.

According to Darby and Lang in their seminal e-book, some professors refuse to make accommodations for students with disabilities even during face-to-face classes.[8] However, this number grows exponentially when that teaching goes on-line. Furthermore, other factors which cause students to struggle with on-line learning, such as race, class, language and cultural barriers, are very rarely considered.

It is up to those of us who are faculty to ensure we have an inclusive and welcoming environment, whether it is on-line or in-person. In an article written by Zhang, et al, it is noted that although on-line learning has become much more common over the past decade, more than two-thirds of faculty reported that they have never made accommodations in their on-line materials, and students are reluctant to ask for accommodations for fear of faculty bias.[9]

Story #2:

A student who has been diagnosed with severe anxiety at a Midwestern university is enrolled in a summer course that is required for graduation in Spring 2021. During the first week of class, the protests nationwide began and were particularly intense in the student's hometown. These demonstrations created an

immediate, visceral impact for the student. Typically a strong student who is able to manage outside stressors, the nature of these incidents resulted in an inability to focus and complete assignments during the first week of summer online class.

College officials dropped the student administratively from the course due to this lack of engagement during the first week. Their adviser, who was not contracted for summer, noticed an email that the student had been administratively dropped from the course, and the adviser followed up with an email and phone call to this student. They stated that they wanted to continue in the course and felt that they could handle it. It took six emails to several different administrators on campus from the advisor to get the student reinstated in the class. Without this intervention, their graduation date would have been delayed by nine months.

First jeopardy: stress of being a student of color during the Black Lives Matter protests during COVID-19. Second jeopardy: first generation student who did not have an advocate to understand how to respond to being dropped or what the repercussions would be. Lack of information about how the system works increased this student's vulnerability. Third jeopardy: poverty and COVID-19. In order to pay for college, this student worked as a certified nursing assistant putting their health in jeopardy as an essential care giver. Because the student is working at a low paying job, there is limited time and money. Furthermore, in this job, physical distancing is not an option.

Marginalized students may feel isolated and believe that it is a polarized community. A recent article states that, "For many people, physical distancing is a privilege... we need to give messaging specific to those conditions". [10]

Story #3:

In a town with less than 2,500 people, lives a third grader who has dyslexia. The family is Latinx. The parents speak minimal English. Even with both parents working (at minimum wage jobs with no health insurance), the

family cannot afford internet. Our university offered tutoring via Zoom for K-12 students with identified disabilities during the pandemic; however, digital inequity made the opportunity for tutoring inaccessible for the student.

First jeopardy: poverty, therefore cannot access the tutoring. Second jeopardy: language and cultural barriers imposed by a racist, stereotyping community and government. Third jeopardy: a culture which sees dyslexia as just unmotivated, in a school district where it is a policy that reading must be taught by using phonics. This child does not learn through phonemic awareness. All of these factors make for a synergistic intersectionality of increased vulnerability.

The Center for Disease Control (CDC) indicated in their May 2020 posting that history reveals that marginalized populations are at the greatest risk for severe illness and high death rates.[11] They also indicated that shared institutions within the community often provide the support and awareness that these individuals need in order to cope with the pandemic. Unfortunately, with the current administration's position on immigration, a great fear has been prevalent in the undocumented immigrant communities.

The typical student may have lost 33% of their anticipated progress in reading and up to 50% in math by fall 2020, with these unexpected voids of learning being highest among black and Latinx children.[12] We would add that students with disabilities are also at increased risk of loss of learning.

Story #4:

Two loving parents have a child who falls on the autism spectrum disorder (ASD) and who is non-verbal. This child hates change and relies on routine, which offers security to this child. This student has a full-time assistant in school. Then, COVID-19 hit. As a result of no face-face school, there were no Individualized Education Program (IEP) mandated aids and services, no paraprofessionals, no speech and language therapy, no occupational therapy, no physical therapy. And no respite for the parents while this student had long

daily meltdowns. This caused and continues to cause emotional stress in every member of the family.

First jeopardy: because this youngster has ASD, loss of school services caused decline in this student's academic and behavioral progress. Second jeopardy: parents forced into fulfilling roles for which they do not have the knowledge and/or skills. Because of lack of resources and information, the family is in crisis. Third jeopardy: the loss of routine and consistency in the daily schedule resulted in the child and the parents experiencing great emotional distress.

Individuals with underlying disabilities are probably at higher risk of developing other symptoms and conditions due to the COVID-19 virus.[13] The family in Story #4 exemplifies this very concept.

Story #5

A student with Intellectual and/or Developmental Disabilities (IDD) and severe asthma (Other Health Impairments) was at home and had a severe asthma attack; the inhaler did not help. The student needed to be transported to the hospital. The only ambulance in this rural town was already transporting someone else and would not return for at least one hour. Due to very limited and sporadic internet access, the family could not conduct a telehealth consultation.

First jeopardy: no access to immediate health care. Second jeopardy: COVID-19 resulted in a limited supply of respirators, and parents could not be with their child in the hospital due to hospital enforcing no visitors. Third

jeopardy: Telehealth works best if one has Broadband internet access. For many in rural America, this is a dream rather than a reality. According to Sundeen, "...55 million Americans cannot reap the benefits of the digital age...14 million in rural areas... access to a hospital or medical clinic are also limited". [14] The lack of digital access and the inability to reach a health clinic in a timely manner or have adequate supplies almost caused the loss of a life. Because of this child's lower comprehension skills and their inadequate functional language skills, the inability for the parents to stay with the child in the hospital caused the child even greater emotional distress which exacerbated the medical condition. If the family had been able to comfort their child via internet interfacing, this may not have happened.

The above stories document the increased challenges that people with disabilities have experienced during the COVID-19 pandemic. They illustrate the many layers and the complexity which put people with disabilities in greater jeopardy. These five stories illustrate the impact of contextual factors during the times of this pandemic. It is the responsibility of each of us to be ally activists for the disability community.

"Our lives begin to end the day we become silent about things that matter."

King ML Jr. Sermon in Selma, Alabama. 1965

Implications for future research: The authors are currently involved in a four-state research project studying students with disabilities and the challenges they face in education, including those due to differences in socio-economic status.

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