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COVID-19 and Individuals with Developmental Disabilities: Tragic Realities and Cautious Hope*

Samuel J. Levine**

I. INTRODUCTION—THE COVID-19 CRISIS

The COVID-19 pandemic has cast the United States, along with the rest of the world, into a time of crisis and uncertainty unlike any other in recent memory. Months into the pandemic, there is scant agreement among scientists, government officials, and large segments of the public, both domestic and abroad, as to determining the causes and workings of the virus, designing appropriate and effective responses to the outbreak, and constructing accurate assessments of the future—or even of the present. Indeed, the availability of concrete information about the virus and its effects is grossly inadequate and often replaced by anecdotal or impressionistic depictions, not infrequently accompanied by rumor and speculation. Perhaps

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* This paper was published in November 2020 during the COVID-19 pandemic. All dates and time descriptions refer to the 2020–21 COVID-19 pandemic unless otherwise stated.

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at some point in the future, with the benefit of the passage of time and access to reliable data, we will better understand important elements of the pandemic. Amidst the current state of knowledge, however, any attempt to learn lessons from the events of the past few months remains a tenuous—if not altogether dubious—enterprise.

Nevertheless, despite the overwhelmingly confusing and confounding aspects of the crisis, certain preliminary conclusions appear to have emerged, including a recognition of the disparate impact of the virus on some segments of the American populace. Specifically, it seems fair to say that vulnerable populations have been disproportionately impacted by the COVID-19 national crisis. Among these populations, individuals with developmental disabilities—including, but not limited to, autism—have faced a number of monumental challenges, bringing about numerous adverse effects. Significantly, in addition to exacerbating some of the preexisting systemic conditions that ultimately gave rise to these calamitous results, the crisis has exposed the underlying reality of society’s failure to provide appropriate services and supports to individuals with developmental disabilities, in at least three separate but interrelated areas: special education, mental health, and physical health. Based on an examination of information that has become available, this Essay briefly surveys the tragic effects of the crisis in each of these areas.

Conversely, the Essay concludes with the suggestion that out of these tragedies—somewhat counterintuitively, if not ironically—there may grow a glimmer of hope toward the future. In particular, though to a lesser degree, other segments of society are likewise experiencing challenges in the areas of education, mental health, and physical health—and many individuals and

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3. Because of the substantial limitations on obtaining reliable and comprehensive information at this time, this Essay relies primarily upon published news reports and personal reflections of the experiences of individuals with developmental delays and their families during the early months of the COVID-19 crisis. In an effort to achieve a degree of reliability, the Essay cites a sampling of different news outlets, reporting on a range of geographical areas. Some of the articles are written by medical professionals, while others rely on and cite underlying expert scientific studies and opinions. It should be noted, however, that in the context of COVID-19, many scientific studies have been widely and wildly disputed and have often been subject to retractions and, not infrequently, retraction as well.
communities are experiencing these challenges for the first time, in ways that were, to them, previously unfamiliar if not largely unknown. Though perhaps overly optimistic, it can be cautiously hoped that this newfound awareness will bring about a measure of sensitivity, empathy, and understanding, and a determination among society-at-large to respond to challenges that, even under the best of circumstances, have long confronted vulnerable populations.

II. TRAGIC REALITIES

By nearly all accounts, the reality of special education during COVID-19 has largely ranged from inconsistent to virtually nonexistent. Many of the

4. Media and personal reports of the unique challenges to special education in the age of COVID-19 are voluminous. As one of countless examples, the New York Times has published a series of articles, starting as early as March 31, 2020, recognizing that

For most parents and teachers across the United States, school closures as a result of the new coronavirus have left them grappling with their new realities . . . . [b]ut for the millions of students in the United States who are living with disabilities—including those with autism, intellectual disabilities, developmental delays and more—this task has proved especially challenging.


Numerous reports have confirmed the degree to which many students with developmental disabilities have struggled as a result of not having access to their educational environment and related services during the COVID-19 crisis.

According to a more recent report in the Los Angeles Times,

The education of some 760,000 California children with disabilities has been inconsistent at best since campuses shut down in March. Parents’ worries have intensified as they see their children’s hard-fought advances diminishing—and fear that losses will be compounded with more distance learning ahead, said educators, parents and student advocates.

See Kohli, supra note 2.

Moreover, although “[t]he state has mandated that school districts continue to provide special education to students with disabilities as required by federal laws, [it] has waived timelines that allow students to receive assessments and services quickly.” Id. In short, “[s]pecial education attorneys in California say hundreds of clients, especially economically disadvantaged students and foster youths, overwhelmingly are not receiving the education or services they are entitled to, nor are students who need assessments to receive appropriate care.” Id.

Another report notes that “students who are from low-income families are overrepresented in special education, and may not have had devices or Internet access,” which, according to Professor William Koski, Director of the Youth and Education Project at Stanford Law School, can constitute “automatic denial of their free, appropriate public education.” See Anya Kamenetz, Families of Children with Special Needs Are Suing in Several States. Here’s Why., NPR (July 23,
services and supports vital to providing effective special education are simply not transferred or transferrable to distance learning. For example, if students require an assistant in the classroom or a one-to-one aide, the absence of these accommodations generally prevents them from accessing their curriculum.


This report adds that “students with attention deficit or communication difficulties may not be able to focus on computer screens for significant amounts of time. And then, occupational, physical and speech therapists, for example, often touch students to guide them, and there aren’t good substitutes for that over video chat.” Id.; see also Annie Grayer, Laura Jarrett & Yon Pomrenze, Parents of Teens with Special Needs Find Themselves Alone in Covid-19 Lockdown, CNN, https://www.cnn.com/2020/07/06/us/coronavirus-special-needs-education-wellness/index.html

The failure to adequately respond to the educational needs of individuals with disabilities has prompted a growing number of lawsuits, on both state and national levels. See Kamnetz, supra; see also Chris Glorioso & Kristina Pavlovic, NYC Accused of Defrauding Special Education Students During Pandemic, NBC N.Y. (Sep. 22, 2020, 8:56 PM), https://www.nbcnewyork.com/investigations/nyc-accused-of-defrauding-special-education-students-during-pandemic/2630397/ [https://perma.cc/J95W-FQ9F].

5. A report in the Washington Post put it this way:

The nation’s school districts are federally mandated to provide America’s seven million students with disabilities an education tailored to their individual needs under the Individuals With Disabilities Education Act, known as IDEA. Each qualifying child receives an IEP, or Individualized Education Program, which lays out the services the student is required to receive.

But receiving all those services was nearly impossible in the spring, when schools, overnight, shifted to remote learning. There had been no plans to deliver services like occupational or physical therapy to special education students, and parents, who had come to depend on schools to care and educate their children during the day, were suddenly at home with them, untrained and unable to fulfill an IEP.

Perry Stein & Valerie Strauss, Special Education Students Are Not Just Falling Behind in the Pandemic—They’re Losing Key Skills, Parents Say, WASH. POST (Aug. 7, 2020, 8:25 AM), https://www.washingtonpost.com/local/education/special-education-students-are-not-just-falling-behind--theyre-losing-key-skills-parents-say/2020/08/05/ec1b91ca-cff0-11ea-9038-a089b63ac21_story.html

6. See, e.g., Kohli, supra note 2 (reporting that “[d]ata from the Los Angeles Unified School District, which has 64,000 students who require special education services, show that they were disproportionately absent from online learning platforms last spring. Only about half of L.A. Unified’s middle and high school students with disabilities were active once a week on Schoology, one of the district’s primary learning platforms, by late May, according to a district report. That’s about 15 percentage points lower than the rates for students without disabilities.”); see also Devin Dwyer & Janet Weinstein, Parents of Special Needs Kids in ‘Panic Mode’ as Virtual Learning Falls Short, ABC NEWS (Sep. 30, 2020, 2:00 AM), https://abcnews.go.com/Politics/parents-special-kids-panic-mode-virtual-learning-falls/story?id=73293360 [https://perma.cc/7WS8-HVTP]; Hallie Levine, As School Returns, Kids
In addition, related services, such as occupational, physical, or speech therapy and individual or group counseling, are not readily susceptible to online delivery, and their absence further impedes the educational process.  


7. See, e.g., Kohli, supra note 2 (observing that “the personal stories of parents and educators grappling with these responsibilities reveal overwhelming challenges, failed attempts to secure help and, ultimately, the realization that in many cases, the direly needed hands-on services of therapists are not performed well through a computer screen”). In the words of Paul Luelmo, Assistant Professor in the Department of Special Education at San Diego State University: “I have spent most of the summer rethinking . . . how do we take these evidence-based practices in an online environment? How do we provide equitable access to the families that need it the most? . . . I wish I had the answers, but I really don’t.” Id.; see also Kristen A. Graham, ‘He’s Not Being Educated’: For Students with Autism and Severe Disabilities, the Pandemic Is a Disaster. What Comes Next?, PHILA. INQUIRER (Aug. 24, 2020, 5:00 AM), https://www.inquirer.com/education/covid-special-education-students-services-lacking-20200824.html [https://perma.cc/FD87-TEFX]; Jaclyn Lee, Parents of Special Needs Children Push for In-Person Learning, Fear ‘Being Left Behind’, 6ABC NEWS (Aug. 18, 2020), https://6abc.com/education/parents-of-special-needs-children-push-for-in-person-learning/6374618/ [https://perma.cc/JJJ6-MEBW]; Serena McNiff, Kids with Special Needs Struggling To Receive Good Care During Pandemic, US NEWS (Aug. 20, 2020, 6:39 AM), https://www.usnews.com/news/health-news/articles/2020-08-19/kids-with-special-needs-struggling-to-receive-good-care-during-pandemic [https://perma.cc/A7QU-SSK6]; Stein & Strauss, supra note 5 (reporting that “[e]ven for schools that specialize in teaching students with learning disabilities, the challenges with remote learning were profound. When schools closed in March, St. Coletta Special Education Public Charter School moved swiftly to attempt to fulfill its students’ IEPs. The school in the nation’s capital—which serves 270 students of all ages with severe intellectual disabilities—moved its one-on-one sessions with students online. Physical therapists and speech therapists made online appointments with students . . . . Despite the efforts, only about 50 percent of students participated in virtual learning. The other students received little special education services, though teachers reached out to them and posted all assignments online.”).

8. See, e.g., Perri Klass, M.D., The Pandemic’s Toll on Children with Special Needs and Their Parents, N.Y. TIMES (July 27, 2020), https://www.nytimes.com/2020/07/27/well/family/children-special-needs-pandemic.html [https://perma.cc/3LP5-5SQZ] (reporting that although “[m]any children had academic and social issues being at home”). According to Dr. Marilyn Augustyn, Director of the Division of Developmental and Behavioral Pediatrics at Boston Medical Center and Professor of Pediatrics at Boston University School of Medicine, “[F]or kids with developmental challenges, the challenges got exacerbated by Covid,” and “[s]ome children aren’t getting their therapy, some miss being in the classroom, and some parents decided to stop medications, or couldn’t get refills.” Id.

For a small percentage of students, including some students with developmental disabilities, there may be advantages to distance learning, including less distraction from other students as well as less social pressure, potential ostracization, and bullying. In addition, some students with developmental delays are adept at technology and may learn better online than in-person. Still, as the reports have documented, for the overwhelming majority of students who are in special education programs, the pandemic has posed a nearly unmitigated detriment to the educational
Second, individuals with developmental disabilities may require mental health treatment for a variety of conditions, including different forms of anxiety, and often have difficulty with lack of structure and changes in routine. Necessary mental health treatment has been severely limited under the COVID-19 crisis, and here too, online sessions, even if available, have experience, both academically and socially. In fact, according to Dr. Eileen Costello, Chief of Ambulatory Pediatrics at Boston Medical Center, “Kids tell me in the office, I miss my friends, even kids who are quirky, for whom going to school is being around other kids, whether they’re their friends or not.”


9. Relying on both his own personal experiences and interviews with experts, Richard Engel has reported powerfully on the effects of the pandemic on children with special needs and on their families. See Richard Engel, Opinion, Kids with Special Needs Are Not OK Right Now. Neither Are Parents, TODAY (Aug. 10, 2020, 4:00 PM), https://www.today.com/parents/richard-engel-kids-special-needs-are-not-ok-right-now-t188987 [https://perma.cc/DW4L-K67Q].

[F]amilies, doctors and advocates for children with disabilities say the disruption caused by COVID is reverberating throughout the entire special needs community. Doctors tell me children with autism are among the most affected. Their disorder seems almost custom-built to kick into high gear when everything they know suddenly turns upside down.

Kids with autism often have trouble dealing with change. They get easily overwhelmed by sounds and new experiences. They often regulate by self-stimulation or “stimming.” Sometimes, they lash out in frustration and tantrums. They can get violent and do self-harm, a strong sensory input.

Id. Engel quotes extensively from Dr. Jenny Radesky, Assistant Professor of Pediatrics at the University of Michigan Medical School, who explains that for children with autism,

[T]he world feels overwhelming because you have all of this visual stimuli, auditory stimuli, just the feelings of things on your skin or your taste or the way your body is moving, it feels overwhelming to kids because their brain connections take in too much of all this information. They can’t integrate it and filter in what’s important and filter out what’s irrelevant . . . So, the world kind of feels like an extra loud, bright, overwhelming place. And that’s one reason why kids develop such a fear of new things, the neophobia, because they don’t want to have to suddenly learn a brand new environment and all these brand new faces. And that’s why sameness feels so good, because the same food or the same house that looks or tastes exactly the same way every time is comforting.

All of these big changes around COVID have been especially disruptive for kids with autism.

often been substandard. The inability to obtain effective treatment, the sudden and drastic interruption to any sense of routine, an ongoing and increasing sense of uncertainty, and seemingly ubiquitous reports of a lethal pandemic have all combined to produce substantially adverse mental health outcomes for many individuals with developmental disabilities.10

Third, the rate of both illness and death from COVID-19 has been measurably higher among individuals with developmental disabilities than among most others.11 The reality of living in group homes has rendered many

10. See, e.g., Klass, supra note 8 (explaining that “[f]or many children, the emotional issues and anxieties manifest in sleeping problems and eating problems” and citing Dr. Radesky, who found that “some children were showing angry outbursts, intense crying episodes, signs they were emotionally dysregulated”).

In an article in the New York Times, Dr. Perri Klass details one of countless examples of this dynamic: Rafael was a nine-year-old on the autism spectrum who had attention deficit hyperactivity disorder, anxiety, and sensory issues. Before the pandemic, Rafael was in a program in the Bedford, Massachusetts, public schools designed for children with autism. Dr. Klass reported that through the program, Rafael was placed in a special classroom, but he was also a member of the regular third-grade class, and could join them for morning meeting or some academic subjects. He had a dedicated aide who worked with him when he got anxious. This was his first year in the school, and the beginning of the year was tough, but by March, things were going well.

Id. As the pandemic set in, however, Rafael became depressed, and he lost seven pounds, prompting his pediatrician to prescribe a medication to stimulate his appetite. Rafael’s mother also observed him becoming “very aggressive” and “looking for the sensory stimulation that comforts him—the blankets, even when it’s hot, or the TV turned up very loud.” Id.; see also Gene Myers, NJ Group Home Residents with Disabilities Have Been Isolated Too Long, Advocates Say, N.J. HERALD (Aug. 17, 2020, 5:16 AM), https://www.njherald.com/story/news/2020/08/17/nj-group-home-residents-with-disabilities-have-been-isolated-too-long-advocates-say/42255613/ [https://perma.cc/7BQG-2LVL].


The report further explains that according to Scott Landes, Associate Professor of Sociology at Syracuse University and co-author of the study,

[T]here are two reasons for the high death rates. People with developmental disabilities are far more likely to have a preexisting health condition, such as respiratory disease, that adds to their risk. They’re much more likely, than even elderly people, to live in a setting with roommates and staff like group homes where two or four or 10 or more people live together. About 13% to 20% of people with developmental disabilities live in such settings . . . compared with only about 6% of people over age 65.

Id.
to be particularly vulnerable to the physical health effects of COVID-19, while additional preexisting health conditions, not uncommon among individuals with developmental disabilities, have been an additional contributing and aggravating factor.

12. Indeed, Professor Landes’s study shows that “people with developmental disabilities who live in group homes have some of the highest death rates from COVID-19 in the country.” Id. According to Professor Landes, the high rate of death is disturbing, but it’s not surprising . . . . They’re more likely—four times more likely, we’re showing—to actually contract COVID-19 than the general population . . . . And then if they do contract COVID-19, what we’re seeing is they’re about two times more likely to die from it.

Id.

It should be emphasized that, beyond individuals with developmental disabilities, many other vulnerable populations have been disproportionately impacted by the COVID-19 crisis. Perhaps most egregiously, according to estimates in forty-three states, residents in nursing homes have constituted more than forty percent of deaths from COVID-19. See Bernard Condon, Matt Sedensky & Meghan Hoyer, New York’s True Nursing Home Death Toll Cloaked in Secrecy, ASSOCIATED PRESS (Aug. 11, 2020), https://apnews.com/212ccd87924b6906053703a00514647f [https://perma.cc/E2H6-PB3U].

Moreover, it appears likely that the numbers reported in New York, already shockingly high, may have been undercounted. See id.

13. In addition, the COVID-19 crisis has brought about months of severe restrictions on family visitations to group homes, presumably increasing the physical impairments of those living in the homes and undoubtedly exacerbating their mental health challenges. Here too, the negative effects were anticipated early in the pandemic, and the concerns have been borne out in the ensuing months.

For example, an article dated March 24, 2020 quoted the observation of the president of an organization that operates group homes that, for many individuals on the autism spectrum, “[S]tructure is the key to everything . . . . But now, they’re not going to their day program or they’re not seeing their families or making that trip to the ice cream parlor. All those things are being impacted without a real good understanding of why.” See Marcia Greenwood, Ban on Visits to Group Homes for the Disabled a Devastating Blow for Families, DEMOCRAT & CHRON. (Mar. 24, 2020, 10:30 AM), https://www.democratandchronicle.com/story/news/2020/03/23/coronavirus-rochester-monroe-county-ny-ban-on-visits-to-group-homes-devastating-for-families/2896959001/ [https://perma.cc/P737-P9HD].

By June, the reality of these challenges had been widely acknowledged and protested. According to one article, “Tens of thousands of people living with special needs inside small group homes in New York who haven’t been able to see their loved ones believe they’re the forgotten ones during the COVID-19 pandemic. Now, a group of lawmakers are taking action.” See Dan Krauth, Coronavirus Update: Group Home Residents with Special Needs ‘Forgotten’ During Pandemic, EYEWITNESS NEWS (June 11, 2020), https://abc7ny.com/group-home-coronavirus-new-york-ny-cases-in/6241149/ [https://perma.cc/ZK5L-HHHH].

The article includes a report on Dave Guerrera and his wife Mona [who] haven’t been able to hug their son Joey since March. He’s 34 years old but has the mind of a 2-year-old.
III. **CONCLUSION—CAUTIOUS HOPE**

Among the numerous tragic realities that the COVID-19 crisis has both caused and exposed, the societal failure to adequately include, accommodate, and protect individuals with developmental disabilities stands out as particularly notable.\(^\text{14}\) Of course, not all of the tragedies that have occurred would or could have been prevented entirely, but the degree of harm might have been limited or mitigated if society had established appropriate safeguards and supports for individuals with developmental disabilities. Moving forward, even beyond the pandemic, it behooves us as a society to recognize and learn the lesson that, although COVID-19 is an extreme example, for many individuals with developmental disabilities, even in the best of times, challenges arise in the areas of special education, mental health, and physical health, albeit usually in a less drastic manner. These ongoing and everyday challenges must be acknowledged, understood, addressed, and remedied.

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> “We really miss him,” Dave Guerrera said. “When this first happened, he’d see me and be all excited and laugh and happy. But as these weeks have gone by, I see depression in his face, and it’s not good.”

> They haven’t been allowed to visit the group home where Joey lives with three other residents.

> “He must be thinking we are horrible, like we abandoned him or something,” Dave said. “I don’t want him to think that.”

> The Guerreras live a mile away and are used to seeing their son every day and taking him out of the home on weekends, but no visitation has been allowed at any of the state’s more than 7,000 group homes since March.

*Id.*

14. *In the words of Richard Engel,*

> Our son Henry is not doing very well with the COVID lockdown. I won’t bother with the perfunctory caveats about all children suffering without school, and all families struggling in this climate of fear and isolation, because it’s only partially true. I think we all know by now that this has not been a collective experience and that families with money, health, real estate and live-in help are doing far better than those without.

> If anything, the coronavirus pandemic has revealed the differences in our society more than our similarities. Extreme pressure, applied to a society, a diamond or an individual mind, eventually exposes all the hidden cracks.

> Henry has severe special needs, and COVID has been an absolute nightmare for him and millions of other children like him.

Engel, *supra* note 9. Indeed, as Dr. Costello observed, “It’s difficult to manage a child with a disability full time on your own. . . . This is exposing all the cracks, the stress of raising a child with a disability.” Klass, *supra* note 8.
Somewhat ironically, and cautiously optimistically, it might be hoped that the broader societal experience during the COVID-19 crisis will serve as an impetus toward greater awareness and understanding of the challenges that confront individuals with developmental disabilities on a daily basis. After all, as a result of COVID-19, to some degree nearly all segments of society have faced challenges in the areas of education, mental health, and physical health. Indeed, large segments of the American populace have experienced, for themselves, their families, and their friends—many for the first time—such challenges as: difficulty in accessing education; unprecedented attention to mental health issues, particularly for children; and sudden and chronic physical health issues. Having lived through these challenges, perhaps those who have been insensitive, unaware, or oblivious to the everyday realities of individuals with developmental disabilities will now find it within themselves to work to bring about the real change necessary to value, protect, and include the most vulnerable populations among American society.¹⁵

¹⁵. Like many scholars and advocates, in my study of the biblical story of Joseph, I have similarly suggested that when others personally experience some of the challenges facing individuals with disabilities, that experience can help instill a measure of empathy and understanding, which, in turn, will hopefully lead to actions demonstrating a newfound sensitivity and appreciation of societal responsibilities. See Samuel J. Levine, Was Yosef on the Spectrum? Understanding Joseph Through Torah, Midrash, and Classical Jewish Sources (2019).