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Perspectives of Immigrant Families and Persons with Disabilities During COVID-19

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Plain Language Summary

COVID-19 is hard for immigrants and people with disabilities. We interviewed 12 immigrant families in New York City who have a child with a disability. Parents were afraid they would have to leave the United States. Families needed support and technology from schools. Families also found that hospitals and medical centers did not have information in Spanish. Parents were also afraid to get money from the government.

Background

In early 2020, the coronavirus—also known as COVID-19—took the world by storm. As of November 20, 2020, a total of 57,365,029 cases were reported globally and 11,854,203 cases within the U.S. alone. The highest number of COVID-related cases and deaths have occurred in the U.S., followed by India and Brazil. Within New York City (NYC), there have been a total of 292,718 cases since the start of the pandemic, and 12,071 cases over the past 7 days (Centers for Disease Control and Prevention [CDC], 2020b; Johns Hopkins University of Medicine, 2020). With the arrival of colder weather throughout the country, the number of COVID-19 cases are expected to grow until vaccines are approved and implemented (Argulian, 2020). Aside from the devastating health effects of the virus—namely, widespread mortality, illness, and hospitalizations—the COVID-19 pandemic has also created a multitude of economic, social, political, and psychological consequences.

Adapting to the changes required by the pandemic has proven challenging to those even in the most ideal of circumstances. For persons at increased risk, including persons with disabilities, communities of color, immigrant communities, and persons with lower socioeconomic means, the negative effects of the pandemic have been even more destabilizing and consequential. Structural biases embedded in our social, political, medical, and economic systems contribute to health and other disparities experienced by disenfranchised groups. This has been particularly evident throughout the COVID-19 pandemic, as certain communities have experienced a disproportionate burden of COVID-related outcomes (NYC Department of Health

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This study has been reviewed by Albert Einstein College of Medicine's IRB and deemed exempt in accordance with 45 CFR 46.102(d) (IRB #2020-12344).

All authors played significant roles in study design, execution, contextual framing, and manuscript revisions.

and Mental Hygiene, 2020). In this study, we aim to explore the heightened challenges and compounded stressors experienced by immigrant parents who have a child with a developmental and/or intellectual disability.

COVID-19 Has Compounded Existing Health and Socioeconomic Disparities

COVID-19 has disproportionately impacted disenfranchised communities within the U.S., exposing weaknesses and vulnerabilities in our country's medical, economic, and political systems. Those hardest hit by the pandemic include Black, Hispanic/Latino, immigrant, and lowincome communities, as well as persons with disabilities (Gold, 2020; Millet et al., 2020; Price-Haywood et al., 2020). African Americans and Hispanic/Latinos remain overrepresented among both COVID-19 cases and COVID-related mortality throughout the U.S. (Bibbins-Domingo, 2020). For instance, although only 20% of U.S. counties are predominately comprised of African Americans, 52% of COVID cases and 58% of COVID-related deaths have occurred in disproportionately black counties (Millett, 2020). Cardiovascular disease, respiratory illness, diabetes, chronic kidney disease, and obesity, known risk factors for COVID-19 mortality and morbidity, tend to be more prevalent among diverse populations in the U.S. (Killerby et al., 2020; Stokes et al., 2020). This also includes immigrant groups of both African and Hispanic/Latino origin (Aguayo-Mazzucato et al., 2019; Carillo-Larco et al., 2019; Commodore-Mensah et al., 2018; Kindarara et al, 2017; Sewali et al., 2015). COVID-related hospitalizations were six times higher among persons with these aforementioned medical conditions, while death rates were 12 times higher (Killerby et al., 2020; Stokes et al., 2020).

A variety of barriers and systemic factors contribute to health and socioeconomic inequities in the U.S., particularly among racial, ethnic, and linguistic minority groups and persons with disabilities. The CDC (2020a) have identified five primary contributors to COVID-19-related health disparities. These contributors include: (1) systemic discrimination (i.e., housing, health care, education); (2) limited healthcare access and utilization; (3) overrepresentation of racial and ethnic minorities in essential occupations such as grocery stores, healthcare facilities, factories, and public transit; (4) educational, income, and wealth gaps; and (5) crowded housing conditions (i.e., multi-generational family members in one household). Social and physical determinants of health have significantly contributed to the disparities experienced by disenfranchised communities both prior to and during the COVID-19 pandemic.

Social determinants of health may include access to high-quality education, resources for basic human survival (i.e., affordable grocery stores and housing), medical services, opportunity for economic growth, vocational opportunities, vocational training, community-based facilities (i.e., recreation or community centers, religious institutions), transportation options, social supports, and technologies (i.e., computers, iPads, internet, etc.). Additionally, social norms and attitudes (i.e., discrimination, racism), culture, socioeconomic conditions, public safety, and residential segregation can also influence health outcomes. Physical determinants of health can include built environment (i.e., pedestrian-friendly walkways, roads), natural environment (i.e., green space, climate), housing design, school setting, work setting, physical barriers, exposure to toxic substances and physical hazards, and aesthetics (i.e., lighting, trees; Office of Disease



Prevention and Health Promotion, 2020). Both physical and social contextual drivers have played a major role in disparities observed in COVID-related outcomes.

Immigrant groups have been particularly hard hit by the COVID-19 pandemic. A county-level analysis across the U.S. revealed that counties with more immigrant (specifically, Central American) and Black residents had higher rates of COVID cases. In the Midwestern and Northeastern regions of the U.S., counties with higher concentrations of Puerto Rican residents also had higher rates of COVID cases (Greenaway et al., 2020). Specifically, immigrant populations experience health and socioeconomic disparities at a higher rate than the general population. This is attributed to several factors including poverty, lack of resources, barriers to accessing healthcare services, healthcare treatment biases, variations in culturally specific health practices, mistrust of government and medical systems, stress from acculturation and migration experiences, discrimination, and lack of health data specific to immigrants and refugees. However, it is very important to mention that immigrant communities possess many strengths and cultural practices that promote resiliency, overall health, and wellbeing (Edberg et al., 2011).

The economic consequences of the COVID-19 pandemic have been far greater for immigrants and other racial/ethnic minorities. In fact, the economic fallout from the pandemic has been deemed the most unequal recession in U.S. history. While the 2001 and 2008-2009, economic recessions more equivocally affected the country's population, COVID-19 has been most financially detrimental to immigrants and other minorities, mothers of school-aged children, and low-wage workers (Long et al., 2020). Immigrants and other minorities, who were already at increased socioeconomic risk prior to COVID-19, tend to be employed in industries devastated by the pandemic and pandemic-related restrictions (Bovell-Ammon, 2019). These industries include tourism and hospitality, retail, transportation, and other service sectors (Sönmez et al., 2020). Occupational settings, for certain, have been a major driver of COVID-19 disparities and have created increased risk for potential acquisition of COVID-19 (McClure et al., 2020). Immigrants are also highly represented among low-wage and essential workforce positions in the U.S. Findings from the U.S Bureau of Labor Statistics (2020) indicate that Hispanic/Latinos are overrepresented in healthcare support occupations (i.e., nursing, psychiatric, and home health aides; OT, PT, and other support positions) that require home visits and frequent travel between sites and patient homes, as well as service sector positions.

While social distancing and quarantine requirements have been mandated throughout the pandemic, many immigrants were among those serving on the front lines, risking their own health and safety. A spatial analysis of subway ridership in NYC during the peak of the COVID-19 pandemic (March-April 2020) revealed that the greatest usage occurred among lower income residents, non-White residents, Hispanic/Latino residents, healthcare workers, and essential workers. Interestingly, when the percent of essential workers was adjusted for, these associations were no longer present. This suggests that greater subway ridership in communities of color and lower income comments is likely driven by essential work. Additionally, this study revealed that essential workers in NYC experienced higher rates of COVID-19 infections (Sy et al., 2020). The opportunity to socially distance has also been hindered among some immigrants because of unstable housing conditions, variability in access to COVID-19 testing, food insecurity,



and lack of health insurance (Dunn et al., 2020; Rader et al., 2020; Souch & Cossman, 2020; Tsai & Wilson, 2020; Van Lancker & Parolin, 2020; Wadhera et al., 2020; Wood et al., 2020).

NYC, home to 3.1 million immigrants (approximately 23% of the city's population), is still recovering from the economic blow of the COVID-19 pandemic (Migration Policy Institute, 2020). Even after the passing of the first COVID-19 wave, the city's unemployment rate remains about 7% higher than the rest of the nation. This is attributed to two primary factors. First, because of the high morbidity and mortality rates in NYC when COVID-19 first hit, city and state officials have been hesitant to fully reopen the economy. Second, NYC residents are overrepresented among the industries hardest hit by the pandemic—namely, retail, transportation, hotel and food services, and arts and entertainment (David, 2020). Between March and June of 2020, over 1.5 million New Yorkers filed for unemployment (Lew, 2020; New York Department of Labor, 2020). Financial insecurity, layoffs, unemployment, food insecurity, and inability to pay rent have been higher among immigrant New Yorkers and New Yorkers of color (Lew, 2020; Parrott, 2020). Findings from the U.S. Census Household Pulse Survey revealed that between July and September 2020, approximately 16.1% of households in the New York metropolitan area reported either sometimes or often not having enough to eat within the past week, while 23.5% of renters have reported they have not yet caught up on last month's rent. Additionally, households receiving unemployment insurance and Supplemental Nutrition Assistance Program (SNAP) benefits are still experiencing housing and food insecurity, suggesting that current state benefits are inadequate in providing economic stability (Parrott, 2020).

Challenges for Persons with Disabilities During COVID-19

Persons with intellectual and developmental disabilities (IDD) have also faced heightened health risks and stressors throughout the COVID-19 pandemic. Children and adults with IDD generally have overall higher rates of co-occurring or underlying physical health conditions than the general population (Glover et al., 2017; Perera et al., 2020; Special Olympics, 2020). Adults with IDD are three times more likely to have heart disease, diabetes, stroke, and cancer—known risk factors for COVID-related mortality. Additionally, adults with genetic developmental disabilities are more likely to have compromised immunity and health function, placing them at higher risk if infected with COVID-19 (Constantino, 2020). Certain medical conditions that tend to be more prevalent among children and adults with IDD (i.e., respiratory disease, obesity) also create increased risk for COVID-19 infection and poorer COVID-related health outcomes (Biswas et al., 2010; Perera et al., 2020).

Research from the past several decades has consistently demonstrated that persons with IDD experience shorter life expectancies and premature death at a higher rate than those without disabilities (Forsgren et al., 1996; Forssman & Ekesson, 2008; Glover et al., 2017; Heslop et al., 2014; Hollins et al., 1998). This increased mortality risk is because of several factors, including limited screenings for preventable physical health conditions (i.e., from a primary care physician) and challenges with nutrition and exercise (Perera et al., 2020). In their systematic review, O'Leary et al. (2018) found that persons with intellectual disabilities experienced death approximately 20 years earlier than average. Premature mortality was highest among women,



those with more severe disabilities, and those with co-occurring medical conditions (mainly respiratory and circulatory conditions). Limited access and other barriers to receiving medical care is also believed to contribute to premature death and other health disparities experienced by the IDD community (Williamson et al., 2017). Additionally, many persons with IDD do not have access to high-quality medical care and many physicians (approximately 80%) have not been trained to treat persons with IDD (Special Olympics, 2020). This has created exacerbated health risk during the COVID-19 pandemic. Further compounding disparities experienced by persons with IDD, Black and Hispanic/Latino individuals with IDD have been found to experience even greater health disparities than their White counterparts (Magaña et al., 2016).

In addition to the increased health risks that persons with IDD already face, additional unanticipated barriers and risks have also emerged during the COVID-19 pandemic. Persons living in group homes, supportive living environments, inpatient facilities, and other congregated settings are at greater risk of COVID-19 acquisition and do not possess the same opportunity to socially distance from other individuals (Perera & Courtenay, 2018). Prior to the COVID-19 pandemic, shifts from institutionalized living to community-based living was a celebratory success for the IDD community. However, with the emergence of COVID-19, persons living in the community or with family members have faced new, unanticipated challenges. A study from Navas et al. (2020) found that families are struggling with changes in routine. Health safety measures have taken priority over leisure and other activities. In a separate qualitative study of 77 ethnically, linguistically, and demographically diverse families of children with IDD, Neece et al. (2020) found that parents' greatest challenge was caring for their children at home while losing many essential services. Additionally, parents expressed concerns about how loss of quality services, socialization opportunities, and remote schooling may impact their child's development.

Interruption to in-person medical care, socialization opportunities, job training, and schooling has been a devastating consequence of the COVID-19 pandemic. The majority of individuals with IDD require critical therapies and in-person care (Constantino et al., 2020). Changes in routine care and access to regular clinical and educational services can escalate stress and problematic behaviors. Additionally, social isolation and loss of community supports increases risk of abuse and exploitation (Courtenay & Perera, 2020). The cancellation of summer programs such as Extended School Year (ESY) and other social and educational programs has been a huge loss for both persons with IDD and their families (Constantino et al., 2020; Embregts et al., 2020; Navas et al., 2020). Telehealth services and remote learning thought advantageous in many regards, also present major limitations. For families with limited financial resources, or those without access to internet and technological devices, remote learning and telehealth may not be a feasible option. Some clinical services (i.e., physical examination, medication management) are best conducted in person (Constantino et al., 2020; Galea et al., 2020). Additionally, because of technological (i.e., digital divide) and communication barriers, some persons with IDD have experienced barriers in receiving pertinent COVID-related health information from local, state, and federal health agencies (Courtenay & Perera, 2020; Embregts et al., 2020).



Children and adults with IDD also face increased risk for mental health stressors. Co-occurring psychiatric conditions and symptoms are typically more prevalent among persons with IDD. However, existing research suggests there is some variability in the prevalence and magnitude of mental health co-morbidities experienced by persons with IDD. This can depend on both the type of disability and the measures and definitions used to operationalize psychiatric symptoms and conditions (Buckles et al., 2013; Cooper et al., 2007; Einfeld et al., 2011; Hughes-McCormack et al., 2017). For example, in their systematic review of epidemiological dual-diagnosis studies on adults with intellectual disability, Cooper and Van der Speck (2009) found that persons with intellectual impairment were more likely to experience mental health problems than the general population. However, persons with Down syndrome were less likely to have mental health concerns when compared to the general population. Nevertheless, mental health comorbidities and inequities among persons with IDD are of concern and should remain a top priority for clinicians and researchers (Krahn & Havercamp, 2019).

Although research on the psychological impact of large-scale disease outbreaks (i.e., influenza pandemics, Zika virus, SARS, Ebola) is sparse, the impact of previous national and global disasters on mental health has been well studied. After disasters such as Hurricane Katrina and the September 11th attacks, sociodemographic factors, vulnerabilities prior to the event, loss of personal items or family members, exposure to multiple stressors, and financial loss were all associated with negative mental health outcomes such as post-traumatic stress disorder (PTSD) and depression (Galea et al., 2020; Neria et al., 2008; Tracy et al., 2011; Vlahov et al., 2004; World Health Organization, 2020). Similar mental health concerns, including PTSD and depression, have been on the rise throughout the COVID-19 pandemic. In their systematic review of 24 studies on COVID-19 related mental health outcomes, Brooks et al. (2020) found that prolonged quarantine has been associated with depression, post-traumatic stress, anger, and confusion. The severity and magnitude of these mental health symptoms are influenced by quarantine duration, financial loss, stigma, boredom, frustration, lack of necessary supplies or information, and fear of infection. Taking these factors into consideration, we hope to better understand the mental health and other stressors that immigrant families and persons with disabilities may be dealing with during this unprecedented time. In this paper, we hope to create a platform for immigrant families who have a child with a disability to voice their concerns and struggles.

Research Question and Study Aim

Because of the complex and compounded stressors that both immigrants and persons with disabilities are facing during the COVID-19 pandemic, we hope to gain a more nuanced understanding of the experiences and perspectives of these families. More specifically, we aim to address the following research question: What are the experiences and stressors of immigrant families of children with disabilities during the COVID-19 pandemic?



Methodology

Setting

This study was conducted at the Rose F. Kennedy Children's Evaluation and Rehabilitation Center (RFK CERC) at Albert Einstein College of Medicine, the University Hospital for Montefiore Medical System, in the Bronx, New York. RFK CERC is an interdisciplinary, tertiary care center that provides diagnostic and clinical services to both children and adults with developmental and intellectual disabilities. Services include, but are not limited to, speech and language therapy, occupational therapy, physical therapy, developmental behavioral pediatric care, primary care, case management, psychoeducation, ophthalmological evaluations, mental health services, health education, nutritional counseling, dental care, and audiology.

Bronx County, New York, is a racially, ethnically, and demographically diverse county. Fifty-six percent of its residents identify as Hispanic or Latino (vs. 19% in NY state and 18% nationally) and 29% identify as African American (vs. 14% in NY and 12% nationally). The Bronx is also one of the poorest counties in the U.S., with 29% of its residents living below the federal poverty line (vs. 15% in NY and 14% nationally; Emory University, 2020). Out of all New York counties, New York ranks 62/62 for overall health outcomes, quality of life, poor physical health days, and poor mental health days. In addition, Bronx residents have higher rates of diabetes and asthma than the national and state averages. These physical and mental health vulnerabilities are likely due to the high level of poverty most residents experience. Approximately 38% of children from the Bronx live in poverty, 39% of residents experience severe housing problems, and 32% experience severe housing cost burden (University of Wisconsin Population Health Institute, 2020). As of November 30, 2020, Bronx County has the 5th highest COVID-related death count in the nation, with a cumulative total of 5,026 deaths (Johns Hopkins University, 2020). NYC was hardest hit during March and April of 2020. During this time, RFK CERC patients who had either contracted COVID-19 or who had a family member with COVID-19 were flocking to local hospitals in large numbers.

Population

The majority of Hispanic/Latino immigrant families who receive services at RFK CERC have emigrated from Mexico, the Dominican Republic, or Ecuador and currently reside in the Bronx. Most immigrant families seen at RFK CERC are comprised of a two-parent household and are with lower socioeconomic means. The mothers often stay home to care for their children. The fathers generally work in Manhattan, usually as a cook or construction worker. Most, if not all, are undocumented and work off the books. They work long hours, 7 days a week—leaving early in the morning and not returning until 11:00pm or later. Most parents have less than a 2nd grade education and have come to the U.S. in search of a better life. While some parents are bilingual (Spanish and English speaking), most speak only Spanish. All families who receive clinical services at RFK CERC have a child with special needs. The most common conditions treated include autism spectrum disorder, intellectual disability, speech and language delays, Down syndrome, learning disability, Attention Deficit Hyperactivity Disorder (ADHD), cerebral palsy, or global



developmental delay.

Recruitment

Convenience sampling was used to recruit study participants. Families who participated in this study receive treatment services with a bilingual social worker at RFK CERC. Parents attend a weekly Spanish-speaking parent-support group and receive family psychotherapy. Their children also receive disability treatment services up to 3 times per week. Child treatment services include individual psychotherapy; weekly speech, occupational, and physical therapy; social skills training; and medical care with developmental pediatricians. Children can receive services at RFK CERC from birth through adulthood.

Data Collection and Analysis

Semistructured interviews were completed with 12 parents from Spanish-speaking countries, including Ecuador, Mexico, and the Dominican Republic. Interview questions (Table 1) were administered in Spanish by a bilingual pediatric social worker. Parent responses were transcribed and then coded. Using a conventional thematic analysis approach and inductive inquiry, codes were then grouped into four primary themes. These main themes are discussed further in the results section.

Table 1Semistructured Parent Interview Questions

Spanish	English
Como estas?	How are you?
Tienen comida?	Do you have food?
Tienen dinero para pagar la renta?	Do you have money to pay the rent?
Como estas emocionalmente?	How are you emotionally?
Como estan con las clases en remote para usted y sus hijos?	How is remote learning coming along for you and your child?
¿Las escuelas han traducido información sobre aprendizaje remoto?	Have the schools translated information about remote learning?
Porque no quieres ir al hospital?	Why don't you want to go to the hospital?

Results

The 12 parents interviewed in this study are first-generation Mexican immigrants and currently reside in the Bronx, New York. Their children receive clinical care at RFK CERC, primarily for global developmental delay, autism, ADHD, learning disability, and mental health diagnoses. As evidenced via parent interviews, these families have experienced an extraordinary amount of stress, both prior to and during the pandemic. All families who participated in this study live



either in a one- or two-bedroom apartment, with typically 5-10 people in a household (sometimes more, including extended family members). Those families living in a two-bedroom apartment typically rent out their second room as an additional source of income. The majority of families interviewed are undocumented, uninsured, and work very long hours, trying to survive on a minimum-wage income. Overall, most of the concerns that parents expressed centered on surviving the COVID-19 pandemic, barriers to accessing essential services, and fear of deportation. We have further classified findings from parent interviews into four themes: (1) fear of deportation, (2) fear of accessing services, (3) financial and economic concerns, and (4) disability-related and schooling challenges.

Fear of Deportation

Because of their immigration status, fear of deportation was the greatest concern that parents voiced and seemed to be an underlying theme in all parent interviews. All families reported that they migrated to the U.S. in hope of providing better opportunities for their children. Because these parents have a child with special needs, these opportunities are even more critical. Returning to their home country would result in loss of educational opportunities and loss of clinical services for their children. For this reason, parents' civil rights are often restricted, and their voices are silenced due to fear of deportation. One parent stated,

I cannot go back home because there are no resources for my disabled child. Plus, I would definitely be arrested for entering the USA illegally."

Another parent reported that he tolerates maltreatment at work because of the risk of potential repercussions, including job loss. Several parents even acquired COVID-19 on the job, while others were required to attend work knowing that others were infected with the virus. Several parents who acquired COVID-19 on the job in such circumstances were later hospitalized and ended up in the Intensive Care Unit. In one such case, the father's employer, fearing a lawsuit, contacted his employee's wife, offering to pay their rent, food, and utilities until her husband was discharged from the hospital. The family was unable to press charges because of immigration status and lack of financial resources.

Fear of Accessing Services

Parents and other family members who contracted COVID-19 reported that they experienced discrimination when seeking medical care. Translation services were not offered at the hospital and families were not informed of their loved one's prognosis. Some families were denied services altogether. Others were afraid to seek medical care at all for fear that they may be deported. Overall, families expressed that they felt marginalized and ignored during their interactions with the healthcare system. Additionally, because of language barriers, parents did not receive adequate information on COVID-19 and their family members' health status. Parents reported that often information was not available in their native language. In addition to challenges experienced within the medical system, parents also expressed fear of accessing unemployment or welfare benefits, such as Supplemental Nutrition Assistance Program (SNAP)



benefits.

Economic Fallout and Financial Problems

Unfortunately, a number of parents and family members have lost their jobs because of the COVID-19 pandemic. These families primarily depend on food pantries for nourishment. These food pantries have long lines and quickly run empty. Immigrant families have struggled, and continue to struggle, during the pandemic because of the lack of resources. One parent reported,

This pandemic is taking a huge emotional toll on our family. I cannot afford to get sick. We do not have the resources or the finances [to not work].

In addition to the economic consequences experienced from job loss, parents were either ineligible or afraid to apply for stimulus checks, unemployment insurance, SNAP, and emergency rent assistance. This has required families to rely solely on charitable donations, which, aside from food pantries, have been sparse.

Disability- and School-Related Challenges

Both parents and children have been required to adapt to an entirely new way of living while losing many of their previous support systems. Remote learning has proven extremely challenging among families interviewed in this study. Most children do not have access to a working computer or internet. While some children received tablets from the Department of Education (DOE), most of these devices do not work. However, many parents fear that, although their child is a U.S. citizen, contacting the DOE to advocate for services and technologies would put their family at risk. These families expressed worry that if they complained to the DOE, they could possibly be detained by U.S. Immigration and Customs Enforcement. As an alternative, parents have been in search of computer and tablet donations for their child's education. One family who has a child with a more severe learning disability has not yet been able to find a school for their child. Because this child has been home since September, the family has needed legal intervention to advocate for their daughter. Overall, parents expressed that home schooling and remote learning has been "a nightmare." Distractibility, particularly among children with autism, learning disability, and ADHD, has been a significant barrier to at-home learning. Additionally, most educational information has been provided to parents in English, without Spanish translation. Parents also reported challenges in getting their child to wear a mask when outside of the home.

Discussion

Consistent with findings from recent COVID-related literature, the families who participated in this study expressed many of the same concerns and challenges that other immigrants and persons with disabilities are currently experiencing in the U.S. during the COVID-19 pandemic. As evidenced through parent interviews, COVID-19 has most certainly exacerbated



the weaknesses of the U.S. political, socioeconomic, and medical systems. For Hispanic/Latino immigrant families who have a child with a disability, these systemic barriers have been catastrophic. The financial and socioeconomic consequences of the pandemic, in conjunction with the challenges of simultaneously trying to manage their child's schooling without necessary resources and support, has placed an extraordinary burden on immigrant families. Continuous fear of deportation (either for themselves or a family member) and fear of interaction with healthcare and social service agencies govern many of the decisions that immigrant families make. Discrimination against Mexican and other Hispanic/Latino immigrants, particularly those who are undocumented, is still very rampant in the U.S. Immigration enforcement, antimmigrant policies, forced acculturation, and discrimination take a heavy toll on the health and well-being of immigrant families (Almeida et al., 2016; Mann-Jackson, 2018; Molina et al., 2016). Children are also very vulnerable to anti-Hispanic/Latino immigrant discrimination and rhetoric, which has increased since the 2016 election (Callaghan et al., 2019).

Discriminatory policies and practices, particularly during times of crisis, create a culture of fear and animosity toward those deemed as "other." The families interviewed in this study described many instances of explicit discrimination because of immigration status, health insurance status, and language status. Furthermore, some families were denied medical care altogether. Others were forced to tolerate discriminatory and potentially unlawful circumstances in the workplace. Unfortunately, healthcare access and quality for immigrants (particularly those who are non-White or from non-English speaking countries) has declined over the past several decades. Limited access to affordable public health insurance programs, decreased protections against deportation, caps on the number of refugees allowed in the country, intimidation in healthcare settings, and discriminatory narratives that discourage use of social services, all contribute to health disparities experienced by Hispanic/Latino immigrants (Khullar & Chokshi, 2019). Immigrant families are at higher risk of food insecurity and financial insecurity. However, immigrants often avoid using any type of public assistance—including SNAP and public health insurance—even when eligible, because of the fear of risking future citizenship (i.e., green card) status (Bernstein et al., 2019; Bovell-Ammon, 2019; Callaghan et al., 2019; Singer et al., 2018).

Immigrant families, including those who have a child with special needs, are experiencing firsthand COVID-related health disparities and have been among the hardest hit by COVID cases, complications, and mortality. Prior to the pandemic, these families already had many cards stacked against them—no health insurance, immigration status, limited financial resources, language barriers, and crowded living conditions. Despite the complex and compounded stressors they face, these families have persevered through life's challenges and worked tirelessly to create a better life for their children. Toxic rhetoric around immigration, in conjunction with discriminatory government policies, should be challenged. Immigrants, both documented and undocumented, and persons of color have been among those serving on the front lines in public service capacities throughout the COVID pandemic. Immigrant workers also play a vital role in sustaining the economy of NYC and the U.S. Most importantly, immigrants enrich and sustain the diverse fiber of our nation and should be celebrated, rather than feared or hated. Similarly, children and adults with IDD also bring richness and diversity of experience and perspective. Changing our narrative on immigration and disability, in conjunction with challenging our own



implicit and explicit biases, can help to strengthen our nation, rather than jeopardize it. In addition, because immigration is such a politically charged topic, securing benefits and other pro-immigration policy changes may best be approached at the state or local, rather than federal, level (Khullar & Chokshi, 2019).

The COVID-19 pandemic has also both created and exacerbated service gaps for immigrant families and persons with disabilities. In addition to healthcare barriers, parents are also struggling to obtain proper educational services and technologies for their children. Because of their immigration status, the families interviewed in this study expressed repeated concern over accessing available emergency government services. Additionally, educational barriers (i.e., lack of internet or working devices) and clinical service gaps (i.e., disruption of care) for persons with disabilities has also been a significant problem that has emerged during COVID-19. Regardless of a parent's immigration status, all children born in the U.S. are legally entitled to a free, public school education. Additional protections are in place for children with special needs. On September 28, 2020, the Office of Special Education Programs (OSEP), a subdivision of the U.S. Department of Special Education and Rehabilitative Services, released a document outlining parents' rights under the Individuals with Disabilities Education Act (IDEA) Part B provision. This document highlights legal provisions indicating that all children with disabilities are entitled to a free, appropriate public education, regardless of type of instructional delivery type. Additionally, school districts are still required to conduct all special education evaluations and team meetings (i.e., Individualized Education Program [IEP]) in a timely manner. Should issues arise, special education legal advocates from the American Bar Association suggest the following: (1) contact the school districts' legal counsel or director of special education; (2) assist families in documenting a student's regressions and setbacks (i.e., maintaining a log); (3) seek support from community-based providers; (4) prepare for potential gaps in treatment; (4) advocate for students to receive schooling in person; (5) if ESY services were missed over the summer, advocate for their continuation during the normal school year (Garcia & Morrow, 2020).

Last, the COVID-19 pandemic has also revealed certain medical and social needs of the IDD community that can create increased risk. Disruption to critical services (i.e., physical therapy, speech-language therapy, etc.), schooling, vocational training, and other programming, as well as increased risk for physical and mental health concerns, has created numerous challenges for individuals with IDD. To reduce the negative impact of these COVID-related challenges, further steps should be taken to protect the IDD community. To address heightened physiological risk, particularly for persons living in group homes, Grier et al. (2020) suggest that families and caregivers create an emergency plan in case COVID-19 is contracted. This includes preparing for a hospital visit and making sure an advocate is present (if necessary) for shared medical decision making. Additionally, if any language barriers are present, families and caregivers should work to develop clear communication pathways so that symptoms can be monitored and treated. Frequent health checks are also advised (Perera et al., 2020). Measures should also be taken to ensure that persons with IDD have access to the proper technologies (i.e., tablets) to continue their treatments and other programs, which can help mitigate some social stressors. Enhancing online support systems has also proven beneficial to persons with IDD (Zaagsma et al., 2020). On a broader scale, ensuring health coverage and accessibility, training



healthcare professionals to provide IDD-inclusive care, prohibiting discriminatory practices, reducing physical barriers to care (i.e., providing ramps), and empowering persons with IDD to make health-related decisions can help to reduce COVID-related disparities and outcomes (United Nations, 2020).

Conclusion

As evidenced in both our study findings and other recent research studies, COVID-19 has created a new set of unanticipated challenges and health risks for both immigrants and persons with IDD. The families interviewed in this study have, unfortunately, experienced extreme stress and discrimination throughout the COVID-19 pandemic. Parents voiced multiple concerns that generally centered on fear of deportation, fear of accessing services, financial and economic stress, and challenges specific to managing their child's disability and education with little to no support. Additional research should be conducted to further explore the unique needs that immigrant families and persons with disabilities encounter during this time of global crisis. Qualitative research can be used to identify general themes and specific needs, while quantitative data collection can help provide a bird's eye perspective on health outcomes and health monitoring. Reducing COVID-19 disparities is absolutely possible but requires collective commitment and flexibility.

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